



Final report of research findings

February 2020

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The Code of Practice for Statistics (the Code) is built around 3 main concepts, or pillars, trustworthiness, quality and value:

- trustworthiness is about having confidence in the people and organisations that publish statistics
- quality is about using data and methods that produce assured statistics
- value is about publishing statistics that support society's needs for information

The following explains how we have applied the pillars of the Code in a proportionate way.

Trustworthiness: IFF Research worked with the Department for Work and Pensions (DWP) to develop the research scope and its aims. The design, delivery and analysis of the research was conducted independently (albeit with further DWP input, via comments at key points, to ensure that the fieldwork, analysis and reporting met the stated objectives). The conduct of the research was in line with the principles set out in both the Market Research Society Code of Conduct and the Government Social Research Code.

Quality: The analysis was conducted using a combination of bivariate analysis and segmentation using Latent Class Analysis. In our commentary, only differences that were significant at 95% confidence have been reported on (unless specifically stated to the contrary).

The analysis and reporting have been quality assured via separate and sequential processes for checking the accuracy of all charts, tables and text against the tabulated data; checking the internal consistency of charts and tables to text and text to table and chart figures; grammatical and drafting accuracy; and consistency and robustness of analysis.

Value: The findings (both quantitative and qualitative) are being used by the DWP to inform its future approach to offering support, where relevant, to individuals in the ESA Support Group and the UC equivalent.

Executive summary

Relatively little is known about the experiences of individuals on the Support Group element of Employment Support Allowance (ESA) and those on the equivalent element of Universal Credit (UC), called 'Limited Capability for Work and Work Related Activity' (LCWRA). The Department for Work and Pensions (DWP) commissioned research to understand more about these individuals and explore what support might be helpful to them in managing their health condition(s) and moving towards work, where appropriate. By 'work', we mean a range of activities, including paid and voluntary work, full, part-time and ad-hoc work, work for an employer and self-employment.

The research consisted of 50 in-depth face-to-face interviews, six focus groups, four peer-to-peer interviews and a survey of 2,012 claimants. The research found that:

- Individuals' daily lives were often shaped by the severity and impact of their health condition(s) with the vast majority (91 per cent) reporting some difficulties with performing usual activities such as housework, family activities, or leisure activities.
- The majority (67 per cent) did not think that paid work will ever be an option for them, with most ruling out work on health grounds (65 per cent of all claimants).
- One in five (20 per cent), however, did have a desire to work and thought they could work at some point in the future. Those interested in paid work were more likely to be interested in part-time work than full-time work.
- One in fifty (two percent) were currently undertaking some sort of paid work; they were predominantly working 15 hours or less, and most said they were already doing the amount of paid work that they wanted to do.
- Around a third (32 per cent) of claimants were interested in receiving support in the future (either with work or with wider issues such as housing, finances or finding volunteering opportunities). Much of the desired support is already offered, but awareness of the current support offer was low. There was particular interest in Access to Work funding, permitted work and the 12-week linking period (although some argued it needs to be longer than 12 weeks). Additional areas of support claimants wanted revolved around the concept of a dedicated support worker, who would, for instance, help to resolve any problems when starting a new job and help with returning to benefits if work could not be sustained.
- The way support is delivered was as important as its content: individuals wanted a support provider to work with them intensively for a sustained period, to allow trust to develop; and wanted someone with good interpersonal skills and lived experience of disability.
- Claimants were divided on whether they welcomed contact from the DWP or JCP regarding the support available, but some did welcome the idea of the DWP/JCP informing them, provided this was sensitively worded and not 'pressuring' them. They tended to be open to contact once every 6-12 months.

- Claimants aged under 50 were more likely to see paid work as a possibility in future; while those on out of work benefits for between one and three years were most likely to express interest in multiple forms of support, indicating that this may be a 'window of opportunity' for offering support, before being out of work becomes entrenched. There are distinct groups of claimants, with differing barriers to work and support needs: this report contains a segmentation describing these differences.
- However, individuals often said they would distrust an offer of support from DWP/JCP even when what was on offer appealed, due to previous negative interactions and a perceived 'hidden agenda' of cutting benefits and costs. A key challenge therefore for DWP and JCP in engaging these claimants will be in overcoming the distrust that many claimants have in DWP/JCP.

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Authors' credits

Lorna Adams and Angus Tindle, Directors, headed up the IFF team responsible for the research. Both have considerable experience in researching employment support and welfare issues, particularly in relation to vulnerable client groups. Siv Svanaes, Associate Director, Sarah Dobie, Senior Research Manager and Sarah Coburn, Senior Research Manager were responsible for day-to-day management of the study. Becky Cartmell, Senior Research Executive, and Sam Stroud, Senior Research Executive, worked on the fieldwork, delivery, analysis and reporting.

Glossary of terms

Access to Work	Access to Work (AtW) is a publicly funded employment support programme that aims to help more disabled people start or stay in work. It can provide practical and financial support for people who have a disability or long term physical or mental health condition. Support can be provided where someone needs help or adaptations beyond the reasonable adjustments that employers are required to make under the Equalities Act 2010. To get an AtW grant, you must have a disability or health condition that affects your ability to work, be 16 or over, and live in England, Scotland or Wales.
Appointee	An appointee is somebody who has been granted the right to deal with the benefits of someone who can't manage their own affairs because they're mentally incapable or severely disabled.
Disability Employment Advisor	Disability Employment Advisors (DEAs) are people employed by Jobcentre Plus to support and upskill work coaches and other members of Jobcentre staff to deliver tailored advisory services to disabled people.
Disability Living Allowance	Disability Living Allowance (DLA) is a benefit that helps people with the extra costs of a long-term health condition or disability. It is being replaced by Personal Independence Payment.
Employment and Support Allowance	Employment and Support Allowance (ESA) is a benefit for people who have an illness, health condition or disability that makes it difficult or impossible to work. ESA offers financial support if you are unable to work, and personalised help so that you can work if you're able to.
Employment and Support Allowance Support Group	The ESA Support Group is for claimants whose WCA outcome considers they have limited capability for work. They are not required to take steps immediately towards moving into work (work-related activities), or to have regular interviews with a Jobcentre Plus advisor.

Employment and Support Allowance Work Related Activity Group	The ESA Work Related Activity Group is for claimants whose WCA outcome considers they will be capable of work at some time in the future and who are considered capable of taking steps immediately towards moving into work (work-related activities). Members will have regular interviews with a Jobcentre Plus advisor.
Entry level qualifications	These are the lowest level of qualification, that provide basic knowledge and skills, and aim to equip the individuals to apply their learning in everyday situations. They are not geared towards specific occupations. Examples include: entry level awards, certificates and diplomas.
Full-time work	There is no specific number of hours that make work full-time, but full-time workers will usually work 35 hours or more a week.
Health score	EuroQol's EQ-5D-3L measurement of health was used in order to assess the severity of health conditions, by asking individuals to indicate the impact of their condition(s) on five key areas: mobility (ability to walk about); self-care (ability to wash and dress); ability to perform usual activities (housework or family or leisure activities); levels of pain or discomfort; and levels of anxiety and depression. ¹ This can be used to calculate a health-related quality of life score. For simplicity, we refer to this as a 'health score' in this report.
Jobcentre Plus	Jobcentre Plus is a brand under which the DWP offers working-age support services, such as employment advisory services. In the context of this report, 'Jobcentre Plus (JCP) office' refers to the physical premises in which Jobcentre Plus services are offered.
Jobseeker's Allowance	Jobseeker's Allowance is an unemployment benefit for people who are actively looking for work.
Level 2 qualifications	This level of qualification provides a more advanced level of knowledge and understanding of a subject and aims to equip the individual to do a variety of tasks with some guidance or supervision. They may be geared towards specific occupations. Examples include: GCSE grades A*- C (and grades 4 to 9 in England), intermediate apprenticeships, Level 2 awards, diplomas and certificates, OCR Nationals, NVQs, Essential Skills, Music grades 4 and 5 and O level grades A-C.

¹ © EuroQol Research Foundation. EQ-5D[™] is a trade mark of the EuroQol Research Foundation

Level 5 qualifications	This level of qualification provides depth of knowledge and understanding of an area of work or study and aims to equip the individual to respond to complex problems and situations. It is suitable for people working as higher-grade technicians, professionals or managers. Examples include: HNDs, NVQs, BTEC Professional diplomas, certificates and awards, Foundation degrees, Diplomas of higher education (DipHE).
Part-time work	A part-time worker is someone who works fewer than 35 hours per week.
Permitted work	People claiming ESA can do permitted work without it affecting their benefit. It is permitted work if: (a) claimants earn up to £125.50 a week; and (b) claimants work less than 16 hours a week. In Universal Credit (UC), claimants who have a health condition or disability and have had their Work Capability Assessment receive a Work Allowance: those who receive money to help with their housing costs can earn up to £287 per month without it affecting their UC payment; and those who do not receive help with their housing costs can earn up to £503 per month before earnings are deducted from their benefit award. UC claimants are not restricted on the number of hours they work to make up those earnings.
Personal Independence Payment	Personal Independent Payment is a benefit that helps people with the extra costs of a long-term health condition or disability. It replaces DLA.
Twelve-week linking rule	The 12-week linking rule protects ESA claimants' benefit for breaks of up to 12 weeks, which means someone who becomes sick again within 12 weeks of leaving ESA may be able to re-qualify for a further 365 days of ESA.
Universal Credit	Universal Credit (UC) is an in and out of work benefit designed to support people with their living costs. Most new claims by people with a health condition or disability are now made to UC with the remaining claiming New Style ESA which has replaced ESA-Contributions based. The equivalent to the ESA Support Group within Universal Credit is UC-LCWRA (Limited Capability for Work and Work Related Activity).

Work Capability Assessment If a person claims ESA/UC because of a health condition/ disability they must have a Work Capability Assessment (WCA). This is a test used by the DWP to determine to what extent a person's illness or disability affects their ability to work. Depending on the outcome of the WCA, people are either deemed to be fit for work, or entitled to ESA/UC. Those deemed not to be fit for work are then placed in one of two groups: the ESA Work-Related Activity Group/UC-Limited Capability for Work, members of which will have regular appointments with an advisor; or the ESA Support Group/UC-Limited Capability for Work and Work Related Activity, members of which do not.

Abbreviations

BAME	Black and Minority Ethnic
BSL	British Sign Language
DEA	Disability Employment Advisor
DLA	Disability Living Allowance
DWP	Department for Work and Pensions
ESA	Employment and Support Allowance
JSA	Jobseeker's Allowance
JCP	Jobcentre Plus
LCWRA	Limited Capability for Work and Work Related Activity
PIP	Personal Independence Payment
UC	Universal Credit
WCA	Work Capability Assessment
WRAG	Work Related Activity Group

Summary

This report presents a summary of key findings from research with claimants in the ESA Support Group and the equivalent Universal Credit Limited Capability for Work and Work Related Activity (LCWRA) group, to learn more about individuals' daily lives, their challenges, support needs, and attitudes to employment. The research comprised in-depth interviews, peer-to-peer interviews, focus groups and a survey.

Aims, background and methodology (Chapter 1)

In 2016, the 'Improving lives: The Work, Health and Disability Green Paper' set out a Department for Work and Pensions (DWP) commitment to undertake comprehensive research to understand how best to engage and support individuals in the Employment Support Allowance Support Group and the Universal Credit LCWRA group. This research therefore set out to better understand these individuals' attitudes towards employment, their wellbeing and aspirations, and the support they currently receive. It also sought to explore what support might be helpful to these individuals in moving closer towards work, where appropriate.²

The research involved both qualitative and quantitative elements. The qualitative strand consisted of 50 in-depth face-to-face interviews followed by six focus groups and a handful of peer-to-peer interviews. The quantitative strand involved 2,012 interviews (1,945 over the phone and 67 online). The research was conducted across England, Scotland and Wales. The qualitative topic guides and survey questionnaire were designed in collaboration with DWP. For brevity, the term 'claimants' is used to refer to members of the ESA Support Group and the Universal Credit LCWRA group. The survey dataset was weighted to correct for non-response, allowing us to report the survey findings as representative of the claimant population of interest, as a whole.

Understanding who is in the ESA Support Group (Chapter 2)

ESA Support Group and Universal Credit LCWRA claimants were similar in many respects to the whole UK population, but were more likely to be older, less qualified, single, and renting their homes; and large minorities had limited digital skills (42 per cent said they were unable or struggle to use the internet) and/or no access to the internet in or outside of their homes (21 per cent).

Claimants' health conditions were wide-ranging and the vast majority (87 per cent) reported multiple conditions. Most (79 per cent) expected their condition to last for the rest of their life, and most did not expect it to improve (only nine per cent expected an improvement). They also typically found their health difficult to predict, with two-thirds (66 per cent) reporting some fluctuation.

Most were a long way from the labour market in terms of their employment history: a quarter (25 per cent) had never been in paid work, only two-fifths (39 per cent) had histories of consistent paid work (defined as having 'mostly been in paid employment' during their working life), and those who had previously worked had typically done so five or more years ago. Many had been on out of work benefits because of a health

² By 'work', we mean a range of activities, including paid and voluntary work, full, part-time and ad-hoc work, work for an employer and self-employment.

condition or disability for a long time: 60 per cent had been so for over five years, and over a third (36 per cent) had been for over 10 years. The in-depth interviews revealed three main routes into the ESA Support Group:

- Those with experience of employment who had left following a specific unpredictable incident (e.g. a heart attack).
- Those who had left work due to a gradual deterioration in their health over time. Some of these claimants felt unsupported or 'managed out' of work by their employer.
- The third group had little or no experience of employment. These were a mix of younger individuals, and those with appointees who reported that the individuals' health conditions had always been a barrier to them working.

Individuals' daily lives (Chapter 3)

Individuals' daily lives were often shaped by the severity and impact of their health condition(s) with the vast majority (91 per cent) reporting some difficulties with performing usual everyday activities such as housework, family activities, or leisure activities. Some were very severely impacted by their health condition or disability e.g. being unable to wash or dress themselves (17 per cent,) confined to bed (seven per cent), in extreme pain or discomfort (36 per cent), or experiencing extreme anxiety or depression (36 per cent). The in-depth interviews found that those whose conditions were more manageable were able to fit their health needs into a routine alongside participation in social or community activities or interests; while, at the other extreme, individuals whose conditions were harder to manage, talked about their daily lives being dominated by health care needs, coping with pain, and medical appointments.

Nearly all claimants (97 per cent) were receiving some kind of support to help them manage their health condition(s), most commonly from a carer, relative or friend (85 per cent) or family doctor or GP (77 per cent). However, the research found that a lack of support for mental health conditions was an issue for some claimants.

The majority of claimants (77 per cent) were receiving additional support in the form of Personal Independent Payment (PIP) or Disability Living Allowance (DLA) payments alongside their ESA/UC claim. The in-depth interviews revealed that those receiving PIP or DLA felt that it made a significant difference to their quality of life. The mobility component enabled people to leave the house, by funding taxis, cars (through the Motability Scheme) or family members' petrol; while the daily living component was put to more diverse uses.

Attitudes towards employment (Chapter 4)

The majority of claimants (67 per cent) did not think that paid work will ever be an option for them, with most ruling out work on health grounds (65 per cent of all claimants). One in five (20 per cent), however, did have a desire to work and thought they could work at some point in the future. Among these, four per cent of claimants thought they could work now if the right job was available and with the right support. In addition, two per cent were already doing some paid work (mostly part-time). The rest didn't know if paid work would be possible (11 per cent).

Of the 20 per cent who were interested in paid work at some point in the future, over half (56 per cent) were interested in part-time work, with 40 per cent interested in

working up to 15 hours per week (equivalent to the current permitted work rules). Of those interested in work, 30 per cent were interested in working full-time (equivalent to 8 per cent of all claimants).

Those interested in paid work were more likely to be aged under 50 and tended to be closer to work in that they had less severe health conditions; had been out of work for less time; had better digital skills; and were more likely to have formal Entry Level or Level 1-5 qualifications. In the in-depth interviews, claimants who felt that work was a possibility were often determined to enter work, with a strong work ethic being part of their identity; and motivations for returning to work went beyond financial rewards (including boosting confidence or self-esteem or being someone who 'contributes' as a worker or taxpayer).

Interest in voluntary work was similar to that for paid work: a minority of all claimants (six per cent) were volunteering at the time of the survey, and a fifth (19 per cent) felt it was a possibility in the future. Voluntary work could be seen as a 'stepping stone' to paid work in the near future, but this was not always the case: those currently volunteering who did not think they could ever undertake paid work (47 per cent) outweighed those who felt undertaking paid work in the near future was a possibility (28 per cent).

Claimants reported multiple barriers to entering employment. Health-related barriers (such as being concerned that health conditions would impinge on ability to gain or maintain employment, or that working would have a negative impact on health) were more prevalent than employment-related ones, but among those who had never worked before, employment-related barriers, such as lack of qualifications, skills or experience, were much more prevalent.

The number of perceived barriers tended to increase with age and with severity of health condition, and was also higher among those with mental health conditions. Those who felt work was a possibility in the near future reported the fewest barriers. The qualitative research also identified a common concern that showing an interest in moving towards work would trigger a Work Capability Re-assessment and cause their current benefit to end.³

Views on employment-related support (Chapter 5)

Around a third (32 per cent) of claimants were interested in receiving work-related support in the future. The majority (68 per cent), however, were not. Unsurprisingly, those who did not think it likely that they would work in future were significantly less interested in support. Interest in support was higher among younger claimants, claimants with mental health conditions, and those closer to the labour market (i.e. who felt work could be a possibility in the future).

Much of the support claimants expressed interest in is already offered by JCP (for instance, as part of Access to Work), however, it emerged in the focus groups that claimants lacked awareness of what is available. Additional areas of support claimants wanted revolved around the concept of a dedicated support worker, who would, for instance, help to resolve any problems when starting a new job and help with

³ Undertaking work-related activity should not affect the result of a Work Capability Assessment and claimants may undertake permitted work. Within ESA, it is permitted work if: (a) claimants earn up to \pounds 125.50 a week; and (b) claimants work less than 16 hours a week. For a fuller definition of permitted work, see the Glossary.

returning to benefits if work could not be sustained. How support is delivered was also important. Claimants liked the idea of having continuity in support over a sustained period of time (to allow trust to develop); from someone with good interpersonal skills and lived experience of disability. There was thus broad support for the concept of a support worker, to deliver this.

Perceptions of and communication with DWP and JCP (Chapter 6)

Opinions were divided in the focus groups regarding whether the DWP and JCP were distinct and different or the same entity. Both tended to be seen in a negative light, although the extent of this varied. Factors leading to negative perceptions of DWP and JCP included: a perceived underlying agenda of benefits cuts and cost savings; past negative experiences of dealing with DWP and JCP; a perceived poor understanding of mental health among JCP staff; and concern that JCP were not sufficiently focused on finding individuals employment appropriate to their capabilities and ambitions. This meant that some individuals distrusted the motives behind any DWP/JCP offer of support, even if they were attracted to what was on offer in theory.

Claimants were divided on whether they welcomed contact from the DWP or JCP regarding the support available. In the survey, four in ten (39 per cent) agreed they would be pleased if DWP/JCP contacted them about this; but a third (32 per cent) disagreed. Those closer to the labour market were more likely to welcome this contact. Similarly, some claimants in the focus groups felt sad and frustrated by the lack of communication about available support, as it implied they had been overlooked; others, however, were happy not to be contacted.

Preferences for communication channels and frequency were varied, however, the broad consensus was that communications repeated at regular intervals (e.g. every 6-12 months) would be necessary so that at least some of them landed at a time when the individual felt well enough to engage with them. The survey revealed a clear preference for communication by letter and phone, rather than text or email.

Segmentation analysis (Chapter 7)

A segmentation analysis of claimants who had not ruled out work on health grounds and were not terminally ill was undertaken to take a multidimensional approach to understanding claimants' work aspirations and support needs.⁴

Two of these segments, together equivalent to 12 per cent of all claimants, were the closest to work:

- **Work ready** (four per cent of claimants). These claimants were more strongly interested in entering work; felt it would benefit their health; were more interested in work-related support; and saw fewer barriers. They felt they could return to work immediately, if they found the right job and with the right support.
- **Interested in support** (eight per cent). These claimants were most interested in work-related support, and their barriers were more focused on knowledge, skills and confidence, and less on health.

⁴ This segmentation was applied to 638 respondents, equivalent to 32 per cent of the sample.

A further two segments, together equivalent to 10 per cent of claimants, had an interest in work but saw it as something that could be possible in the further future:

- Interested in support, but other things to sort first (seven per cent). These claimants were more concerned about their health, both as a barrier to finding a job, and in terms of work making it worse. They were interested in work-related support, but were more likely to have personal or family issues such as debt, housing issues, or caring responsibilities.
- **Equipped, but need time** (four per cent). These claimants were equipped to find work in terms of their knowledge, skills, confidence; in having support for their health condition(s); and not having other family or caring responsibilities. However, they were more likely to say that work could be a possibility in the more distant future (in two or more years' time). This hesitancy seemed to be due to their having more severe conditions and being concerned about the impact of their conditions on their ability to work.

Two segments, together equivalent to 10 per cent of claimants, were furthest away from work and had less interest in support to find paid work:

- **No interest in help, worried/unsure** (nine per cent). These claimants reported the most barriers to working and were least interested in help; and they either had no interest in work or were most unsure about working.
- **No interest in help, desire to be left alone** (one per cent). These claimants were most likely to say they were not at all interested in work, and less interested in work-related support. They were concerned about how their conditions and work might interact.

Conclusions and recommendations (Chapter 8)

Understanding who is in the ESA Support Group and UC equivalent: Claimants in the ESA Support Group and UC equivalent tended to be older, less qualified and with more limited digital skills and internet access than the UK population overall. While the severity of individuals' health conditions varied, the majority experienced some impacts on things like performing usual activities, self-care or anxiety and depression. Many expected their condition to last for the rest of their life and did not expect it to improve. Many of those with a mental health condition were not receiving mental-health related support. The majority were also a long way from the labour market: consistent histories of paid work were relatively uncommon and previous paid work tended to be five or more years ago.

Work aspirations: Most claimants in the ESA Support Group and the Universal Credit LCWRA group have ruled out paid work as being a future option due to their health. A fifth, however, did have a desire to work, but more so for part-time work rather than full-time. A further two per cent are already in paid work, and predominantly already doing as much work as they felt capable of or were comfortable with (mostly part-time hours).

Support needs: The findings show that there is scope for DWP/JCP to engage with some claimants in the ESA Support Group and the UC equivalent to offer them voluntary support in their journey towards paid work. Among those interested in employment, much of the support they say they want covers many elements already being offered or trialled by the DWP/JCP. There was particular interest in Access to

Work funding, permitted work and the 12-week linking period (although some argued it needs to be longer than 12 weeks).

Additional areas of support claimants wanted revolved around the concept of a dedicated support worker, who would, for instance, help to resolve any problems when starting a new job and help with returning to benefits if work could not be sustained. The way support is delivered was as important as its content: individuals wanted a support provider to work with them intensively for a sustained period, to allow trust to develop; and wanted someone with good interpersonal skills and lived experience of disability.

Claimants who are more interested in support include: claimants aged under 50 who were more likely to see paid work as a possibility in future; and those on out of work benefits for between one and three years who were most likely to express interest in multiple forms of support, indicating that this may be a 'window of opportunity' for offering support, before being out of work becomes entrenched. Indeed, the shorter the time that claimants had been on out-of-work benefits, the more likely they were to welcome contact from the DWP/JCP about the employment-related support on offer (as long is this made clear that taking up support is voluntary).

There may also be particular opportunities to support individuals with mental health conditions: while they report the most barriers to employment, they are also more interested in employment-related support and more likely to believe that work would benefit their health.

Challenges: Supporting some claimants in the ESA Support Group and UC equivalent towards work will pose challenges in the following areas:

- **The benefits system:** Claimants experience the current process of applying for benefits as challenging/emotionally taxing, and they feel that their place in the ESA Support Group has been hard-won. Taking up paid employment is therefore seen as high-risk. Awareness of existing initiatives to de-risk paid employment is low; and fear that engaging in work-related activities will trigger a WCA reassessment is common. The wider benefits system is thus perversely incentivising individuals to avoid engaging with work-related support.
- *Employer attitudes and behaviour:* Individuals with previous experience of work reported mixed experiences in terms of whether their employer (or line manager) had been supportive. There was concern about how to find suitable roles and employers, how to communicate health-related needs to these employers, and whether employers would be understanding or flexible enough to accommodate these needs.
- **The DWP and JCP:** Although much of the support claimants say they would like is offered by JCP, a key challenge for DWP and JCP in engaging these claimants will be in overcoming the distrust that many claimants have in DWP/JCP.

1 Aims, background and methodology

This chapter provides an overview of the background to and aims of the research project, as well as details of the research methodology.

The research involved both qualitative and quantitative elements with Support Group claimants (and UC equivalents); the qualitative strand consisted of 50 in-depth interviews followed by six focus groups and a handful of peer-to-peer interviews (four in total)⁵. The quantitative strand involved 2,012 interviews (1,945 over the phone and 67 online).⁶ The methodology used for each of these stages is covered in turn.

This report draws on the findings of quantitative and qualitative research, focusing on the findings of each, according to their relevance to the topic.

1.1 Aims and background of the research

Relatively little is known about the experiences of individuals on the Support Group element of Employment Support Allowance (ESA) and their interest in or need for employment-related support. This is because a large proportion of the research into employment support that has taken place among ESA claimants has focussed on specific interventions or programme evaluations. These, by design, have often been aimed at those closer to the labour market. To an extent this makes sense as – by definition – those in the Work Related Activity Group (WRAG) are closer to being able to find employment. It is also a function of the emphasis placed on trying to help people back to work as early as possible and thereby to prevent the negative spiral of declining health and increasing distance from the labour market that can develop as the length of time on out-of-work benefits increases. However, the majority of ESA claimants are placed in the Support Group: as at August 2018, around 72 per cent of the ESA caseload were in the Support Group; and a further 7 per cent were awaiting their Work Capability Assessment, after which a number of this group will also have been placed in the Support Group.⁷

⁵ This involved individuals in the ESA Support Group interviewing a small number of other individuals in the ESA Support Group.

⁶ The online survey was developed to help make the survey more accessible and to cater for individuals who would not feel comfortable speaking about their condition and experiences over the phone.

⁷ ESA Caseload Statistics as at August 2018 (Source: Stat-Xplore).

This research programme therefore sought to fill the evidence gap around the experiences and attitudes of those in the ESA Support Group and their equivalents in the Universal Credit Limited Capability for Work and Work Related Activity (LCWRA) group.

The research has two main objectives:

- To better understand individuals in the ESA Support Group and the equivalent Universal Credit LCWRA group, going beyond the demographic and claimant data that is available in Department for Work and Pensions' (DWP) administrative data, to look at factors such as work history, relationship with work, wellbeing and aspirations. It also looks at the range of support that this group is currently receiving in terms of health-related support, financial support through other benefits (e.g. PIP) and non-financial support (e.g. use of council-provided or voluntary sector services);
- To conduct **exploratory research** into the types of support that could be both helpful to claimants in managing their condition and/or in their journey towards eventually finding work, where appropriate.

In addressing these objectives, this research project has developed in response to various issues raised in the Work, Health and Disability Green Paper *Improving Lives*,⁸ including:

- A concern that assessing individuals as being eligible for the financial support that is associated with the ESA Support Group simultaneously confers a message that these claimants are not suited to work and cuts them off from employment advice, since they do not routinely have any contact with a Jobcentre Plus work coach;
- A direct commitment to undertake comprehensive research to better understand how to engage with individuals in the ESA Support Group and the equivalent Universal Credit LCWRA group and to explore what interventions are needed to support them effectively;
- An aspiration to halve the disability employment gap, which would entail around a million additional disabled people being in work.⁹

⁸ <u>https://www.gov.uk/government/consultations/work-health-and-disability-improving-lives</u>

⁹ Employment rates amongst disabled people reveal one of the most significant inequalities in the UK today: less than half (48%) of disabled people are in employment compared to 80% of the non-disabled population (Improving Lives: The Work, Health and Disability Green Paper; Department for Work and Pensions and Department of Health, October 2016)

1.2 Methodology

The first phase of the research consisted of the core qualitative elements of the project; face-to-face in-depth interviews with individuals in the ESA Support Group and UC equivalent and focus groups with individuals in the ESA Support Group. This informed the second, quantitative phase of the research. This involved an online and telephone survey of a sample of claimants in the ESA Support Group and UC equivalent. Alongside this survey, a handful of qualitative peer-to-peer interviews were conducted.¹⁰

This section briefly describes the methodology used for each stage in turn. More detailed information on the methodology is given in the Technical Appendix.

1.2.1 Face-to-face in-depth interviews

A total of 50 face-to-face in-depth interviews were conducted with individuals in the ESA Support Group and UC equivalent.

The in-depth interviews focused on understanding individuals' daily lives; approaches to managing health conditions/disabilities; how individuals had come to be in the ESA Support Group or in the equivalent group of UC claimants; receipt of and use of Personal Independence Payment or Disability Living Allowance; attitudes to work; perceived barriers to moving closer to work; and an initial discussion of the kinds of additional support that individuals might want with their health condition and/or with moving closer to work. Interviews lasted between 60 and 90 minutes.

Interviews were conducted in six areas across England, Scotland and Wales: London Borough of Newham, County Durham, Great Yarmouth, Bridgewater, Cardiff and North Lanarkshire. Recruitment took place to quotas set by: primary health condition; receipt of ESA/UC and PIP/DLA; route onto ESA; length of time on benefits; age and gender. Distance from the labour market (based on the individual's perception) was also monitored, to obtain a good cross-section of ESA Support Group members and their UC equivalents. Seven out of the 50 participants had an appointee.¹¹

1.2.2 Focus groups

A total of six focus groups were conducted with individuals in the ESA Support Group who had not previously taken part in an in-depth interview and who had some degree of interest in work. Between four and eight participants took part in each group; 37 participants in total.

The focus groups were structured by the following:

• Age, as the in-depth interviews suggested that attitudes to work, prior experience of working and support needs differed by age;

¹⁰ This involved individuals in the ESA Support Group interviewing a small number of other individuals in the ESA Support Group.

¹¹ An appointee is somebody who has been granted the right to deal with the benefits of someone who can't manage their own affairs because they're mentally incapable or severely disabled.

- Whether the individual's condition was fluctuating or stable or improving, as the in-depth interviews suggested that support needs differed for those with fluctuating conditions; and
- Whether the individual had a definitive, or more tentative, interest in workrelated activity, to understand whether attitudes and support needs differed by this degree of interest.
- All included a mix of genders.

A separate focus group was conducted to include people with hearing impairments, because only one hearing-impaired person had taken part in the in-depth interviews.

The focus groups explored attitudes to work-related activity; and perceived barriers to moving closer to work; and then – building on this – explored in much greater detail the kinds of additional support that individuals might want with their health condition or with moving closer to work. After individuals' spontaneous ideas about the support they might want had been explored, a Disability Employment Advisor (DEA) from Jobcentre Plus (JCP) briefed participants on JCP's current approach to working with individuals with disabilities and health conditions, and the types of support and opportunities available; to allow participants to develop their ideas further.

The focus groups also explored perceptions of JCP and the DWP; how participants felt about the DWP or JCP being the provider of the kinds of support that they might want to take up; and how they felt about the DWP or JCP contacting them about the support on offer.

These were extended groups, lasting 3 hours, to enable exploration of complex issues from multiple perspectives; and to allow both variation of the discussion pace and plenty of short breaks, to accommodate participants' needs.

1.2.3 Peer-to-peer interviewing

A total of four peer-to-peer interviews were completed, by two individuals in the ESA Support Group. Interviewers and respondents were recruited through a local council and a separate charity devoted to helping individuals with health conditions who are looking to enter voluntary or paid work.

IFF Research held a day long training session in the local area with the interviewers, in advance of the interviewing itself. This covered both interviewing technique and more practical or logistical considerations, such as the process of arranging interviews and the importance of informed consent.

1.2.4 Quantitative research

A total of 2,012 quantitative interviews were conducted with individuals in the ESA Support Group and UC equivalent; 1,945 over the phone and 67 online.¹²

A stratified random sampling approach was adopted: younger claimants aged 18-24 and those claiming Universal Credit were less prevalent in the claimant population and so were oversampled to make it possible to achieve sufficient interviews to support separate analysis of findings for these two sub-groups.

¹² The online survey was developed to cater to accessibility requirements and to individuals who would not feel comfortable speaking about their condition and experiences over the phone.

The sample of 8,000 individuals was drawn from contacts supplied by the DWP. The fieldwork outcomes for these 8,000 individuals are outlined in Table A3 in the Technical Appendix.

The questionnaire design was informed by the findings from the qualitative research and a five-day pilot exercise, involving a total of 30 telephone interviews. The interview covered the individual's benefits history; their use of Personal Independence Payment or Disability Living Allowance; their reported diagnosis and prognosis of their health condition(s); general well-being and daily lives, for example claimants' ability to perform their usual activities (housework or family or leisure activities) or to wash and dress themselves;¹³ employment history; attitudes to work; perceived barriers to moving closer to work; receipt of, and interest in, health and employment-related support; and attitudes to receiving communications from JCP and DWP.

Data were weighted in two stages, first to correct for non-response and second to correct for the oversampling of younger claimants and those claiming Universal Credit. The aim of the weighting scheme was to ensure that the final dataset matched the population profile of the ESA Support Group and UC-LCWRA claimants as indicated by the DWP administrative data. Because of this weighting, and the stratified random sampling approach, we report on the survey findings as being 'claimants' rather 'respondents'. In terms of statistical confidence in the findings, the confidence interval is 2.17. This means we can be 95% confident that the true figure lies within + or - 2.17 percentage points of the survey finding.

A more advanced form of analysis, known as segmentation, was used to examine A) responses to a selection of questions together, at the same time and B) group respondents together according to similarities in said responses. The questions that were included in the segmentation were those that provided an indication of claimants' closeness to paid work (i.e. their attitudes towards and their feelings about entering paid work in the future), the perceived barriers that they face in entering paid work and the various forms of support that they said they might be interested in to help them move closer to paid work. The segmentation was conducted using Latent Class Analysis.

For further details of the weighting and segmentation approach, see the Technical Appendix.

Around one-quarter (26 per cent) of those in scope of the study completed an interview. With invalid and ineligible cases removed (e.g. non-connecting or incorrect phone numbers), this rises to 35 per cent. With the application of weights to the final data to correct for non-response, we can be reasonably confident that the survey sample is representative of the claimant population of interest. At an overall level, we can be 95 per cent confident that the survey findings are accurate to within +/- 2.17 percentage points.

¹³ EuroQol's EQ-5D-3L measurement of health was used in order to assess the severity of health conditions, by asking individuals to indicate the impact of their condition(s) on five key areas: mobility (ability to walk about); self-care (ability to wash and dress); ability to perform usual activities (housework or family or leisure activities); levels of pain or discomfort; and levels of anxiety and depression. This can be used to calculate a health-related quality of life score. For simplicity, we refer to this as a 'health score' in this report. © EuroQol Research Foundation. EQ-5D[™] is a trade mark of the EuroQol Research Foundation.

1.2.5 About this report

This report draws on the findings from the quantitative and qualitative research, focusing on each strand according to its relevance to the topic.

The findings are structured as follows:

- Chapter 2 describes the individuals in the ESA Support Group and the equivalent group of UC claimants. It examines their demographic profile and their benefit history, as well as their health condition, employment history and the circumstances in which they entered the Support Group and the UC equivalent.
- Chapter 3 discusses individuals' daily lives, including typical day-to-day activities. It also examines how individuals manage their health conditions, and the impact these have on what they can do. It also discusses any support that they are currently receiving; and their receipt of, and uses for, Personal Independence Payment (PIP) or Disability Living Allowance (DLA).
- Chapter 4 examines individuals' attitudes towards employment, including how they feel about doing paid work, how likely they think they are to work and at what point in future. It also describes perceived barriers to seeking paid employment; experience of and attitudes to voluntary work, and how these interact with attitudes to paid work.
- Chapter 5 considers the extent and type of employment-related support individuals were receiving. It also examines how interested they were in receiving various forms of employment-related support in future.
- Chapter 6 examines claimants' perceptions of the DWP and JCP, and what this
 might mean for the potential of the DWP and JCP to act as providers of some
 of the support individuals wanted. It also describes attitudes towards contact
 from the DWP and JCP about employment-related support; and preferred
 frequency and mode of communication.
- Chapter 7 explores a more advanced form of analysis known as segmentation, which allows us to look at how claimant characteristics, attitudes and behaviours interact with each other, in multiple dimensions.
- Chapter 8 draws together conclusions regarding individuals' work aspirations and support needs, and the potential implications of these.

For brevity, throughout the report we use the term 'claimants' to mean 'members of the ESA Support Group and the equivalent group of UC-LCWRA claimants'.

Please note that qualitative analysis is intended to understand individuals' circumstances, attitudes and behaviour in depth and detail, rather than to be 'representative' or measure the incidence of these attitudes/behaviours. Results therefore show the spread of opinions and give an indication of the in-depth reasons for these opinions or the individual circumstances surrounding them. The interviews achieved are not intended to be fully representative of all members of the ESA Support Group and their UC equivalents.

When describing the qualitative results, the terms 'many', 'some' or 'a few' are used to give a relative indication of the extent to which views were expressed or behaviours reported. The term 'many' is used to mean that a view or behaviour was fairly widespread within a particular group of individuals; while, at the other extreme, 'few'

indicates that a finding applied only to a small handful. 'Some' is used to indicate a middle-ground between 'many' and 'few'.

With regards to the quantitative findings, differences between sub-groups have been tested for statistical significance and only those that are significant are reported on here (unless specifically indicated otherwise).

2 Understanding who is in the ESA Support Group and Universal Credit equivalent

This chapter describes the individuals in the ESA Support Group and the equivalent group of UC claimants. It examines their demographic profile and their benefits history, as well as their health condition, employment history and the circumstances in which they entered the Support Group and the UC equivalent.

2.1 Demographics and benefits history

In this section we describe the overall profile of the claimants, drawing out key demographic differences between the claimant group and the UK population as a whole. We then examine the total length of time claimants had been receiving out of work benefits for a health condition or disability, and how this compares with the length of their current claim.

2.1.1 Demographics

The claimant profile was similar in many respects to the whole UK population, but they were more likely to be older, less qualified, single and renting their homes (Table 2.1).

	Claimants (weighted profile)	UK population ¹⁴
18-24	7%	15%
25-49	47%	55%
50+	46%	30%
No formal qualifications	34%	19%
Own/part-own/mortgage	23%	65%
Renting	66%	34%
Living rent-free, including in a relative's/friend's property	10%	1%
Living as a couple	27%	58%
Dependent children	17%	22% ¹⁵

Table 2.1: Demographics of claimants compared to the UK population

Base: All respondents (2,012), UK Population (63,182,000)

Considering claimants' ages, fewer than one in ten (7 per cent) of claimants were between 18 and 24 years old, compared to 15 per cent of the overall UK population, while nearly half (46 per cent) of claimants were over 50 years old, compared to less than a third of the overall population (30 per cent).

The majority of claimants were renting their homes (66 per cent) and only a quarter owned, part-owned or had a mortgage (23 per cent). The picture in the UK population as a whole is significantly different, where one third rent (34 per cent) and two thirds are home-owners (65 per cent). Ten per cent of claimants lived rent free, including in a relative's or friend's property (compared to 1 per cent of the population). Most claimants were also single with no dependent children (only 27 per cent were living as a couple, and 17 per cent had children).

The proportion of claimants with no qualifications and, separately, the proportion with limited digital skills were notable. Over a third of ESA Support Group and UC LCWRA claimants had no formal qualifications (34 per cent); this rises to 44 per cent among 18-24 year old claimants. In the general population the proportion is 19 per cent. A significant number of claimants are also likely to have limited digital capability (Table 2.2). Nearly three fifths of claimants reported having at least basic digital skills (57 per cent), (compared with 86 per cent of the general population), while two fifths said that they were unable or struggled to use the internet (42 per cent) and one fifth had no access to the internet in or outside of their homes.

¹⁴ Figures based on ONS 2011 Census unless otherwise indicated. Age bands were rebased to those of working age.

¹⁵ Figure calculated by number of couples (x2) and lone parent families (x1) with dependent children, ONS 2017 Labour Force Survey.

Table 2.2: Claimants' digital access and skills

	Claimants (weighted profile)	UK population
No access to the internet	21%	18% ¹⁶
Digital skills, regardless of access:		
Unable or struggle to use the internet	42%	14% ¹⁷
Basic digital skills and above ¹⁸	57%	86% ¹⁹

Base: All respondents (2,012), UK Population (63,182,000)

The limited capacity of many of the ESA Support Group and UC LCWRA claimants interviewed is reflected in the proportion who had someone else complete the survey on their behalf. Although the claimants themselves were initially contacted to complete the survey, a fifth (21 per cent) of respondents had a formal appointee who ultimately completed it on their behalf, and 7 per cent gave permission for someone else such as a friend, carer of family member to complete it for them (Table 2.3).

Table 2.3: Who completed the survey

Respondent type	Respondents
Claimant	72%
Formal appointee	21%
Non-formal appointee	7%

Base: All respondents (2,012)

2.1.2 Benefits history

The total length of time claimants had been claiming out of work benefits because of a health condition or disability varied considerably (Figure 2.1). This includes their current benefit claim and any previous claims.²⁰ A third had been claiming for up to five years (34 per cent); one quarter had been doing so for between five and ten years (24 per cent); while over a third (36 per cent) had been claiming benefits for over ten years.

¹⁶ Cabinet Office Digital Landscape Research published November 2012, 'Offline (never or rarely use the internet)'

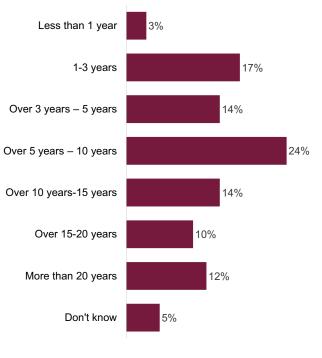
¹⁷ UK Survey Digital Inclusion Scale 2013 as developed for the government Digital Inclusion Strategy. Unable/struggle = segments 1-6.

¹⁸ Basic digital skills and above, reported from the survey data (i.e. the 'Claimants (weighted profile) column in Table 2.2) is a combination of those who reported either "I can use the internet, but only for specific tasks", "I have a basic set of digital skills which allow me to use the internet", "I can confidently use the internet" or "I'm an expert user of the internet".

¹⁹ UK Survey Digital Inclusion Scale 2013 as developed for the government Digital Inclusion Strategy. Basic/confident/expert digital skills = segments 7-9.

²⁰ All claims, and corresponding timelines, were claimant self-reported. They can refer to any previous benefits respondents claimed because of a health condition or disability. The survey question is included in Annex D, question A3.

Figure 2.1: Total length of time on out of work benefits because of a health condition or disability

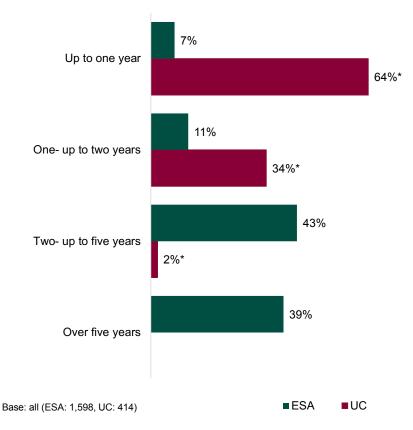


"How long have you been receiving out of work benefits and/or UC because of a health condition or disability?"

Figure 2.2 illustrates the length of claimants' current claim only; and compares those receiving ESA and UC. As might be expected, given UC's more recent introduction, UC Limited Capability for Work Related Activity (LCWRA) claimants had typically been receiving their current benefit for less time than ESA Support Group claimants. Nearly all UC claimants had been claiming for less than two years, and most for less than one year (64 per cent had a claim length of up to one year, and 34 per cent had a claim length of between one and two years). The vast majority of ESA Support Group claimants had a current claim length of between two and five years (43 per cent), or over five years (39 per cent).

Base: all (2,012)

Figure 2.2: Length of time of current claim (in the ESA Support Group or UC LCWRA group)



2.2 Health conditions

This section looks at the nature of claimants' health conditions; the history of the condition (namely the stage in life that it developed) and the reported prognosis and severity.

2.2.1 Nature of claimants' health conditions

The vast majority (87 per cent) of claimants reported multiple health conditions, with 26 per cent unable to distinguish a main condition. The average number of reported health conditions was 4.2. The range was broad, starting at one condition and rising to as many as twenty. As shown in Figure 2.3, only a minority (4%) reported more than ten conditions however.

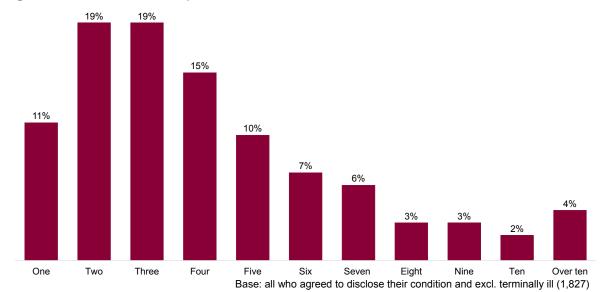
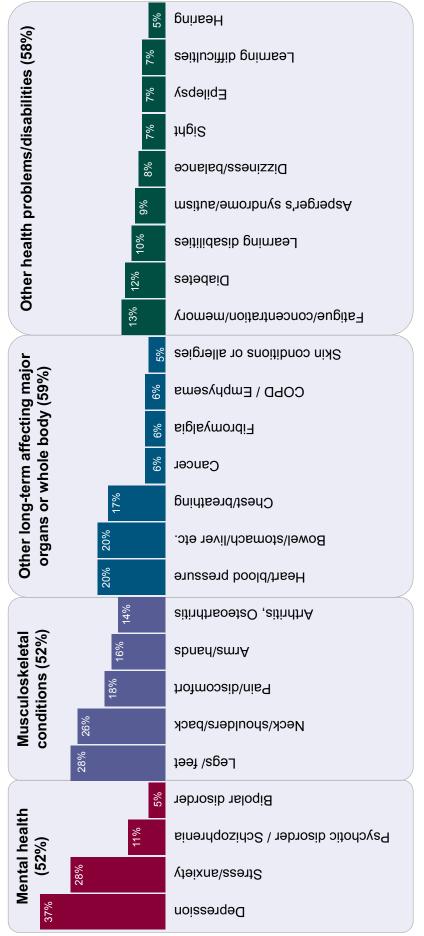


Figure 2.3: Number of reported conditions

As demonstrated in Figure 2.4, a wide variety of conditions were reported; from depression and anxiety, through to physical conditions (musculoskeletal conditions and those affecting major organs) and difficulties with sight, cognitive ability and hearing. Overall, mental health conditions affected 52 per cent of claimants, musculoskeletal conditions affected 52 per cent, conditions affecting major organs or the whole body affected 59 per cent and other health problems or disabilities affected 58 per cent. Considering specific conditions, mental health conditions were most common (37 per cent reported depression and 28 per cent reported stress or anxiety), followed by physical conditions that affect the legs or feet (28 per cent) or the neck, shoulders or back (26 per cent). These were closely followed by conditions related to major organs such as the heart or blood pressure (20 per cent) or the bowel, stomach, liver, kidneys or digestion (20 per cent).

Figure 2.4: Health condition: full breakdown of the most commonly reported health conditions



All health conditions

Base: all who agreed to disclose their condition (2,002)

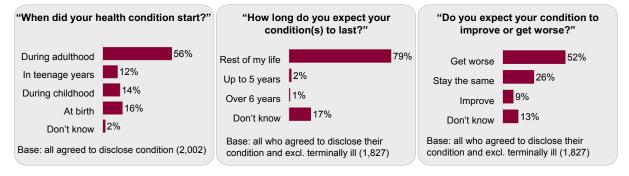
Many other conditions were reported in addition to those outlined in Figure 2.3, each by less than five per cent of claimants. For example, brain injuries (4 per cent), speech problems (4 per cent), agoraphobia (3 per cent), cerebral palsy (2 per cent).²¹

2.2.2 History and prognosis

Claimants were asked at what stage in their life their condition developed and how long they expected it to last. As shown in Figure 2.5, over half (56 per cent) reported that they had developed their condition during adulthood and the remainder were roughly evenly split between birth (16 per cent), childhood (14 per cent) and teenage years (12 per cent). Considering prognosis, the majority (79 per cent) expected their condition to last for the rest of their life and approaching one-fifth (17 per cent) were unsure. Just two per cent expected their condition to be resolved within five years and a further one per cent over a longer period.

Claimants were also asked whether their condition was one that fluctuates and – fluctuation aside – whether they expected it to improve, stay the same or get worse. Around two-thirds (66 per cent) reported some fluctuation. The majority either expected their condition to get worse (52 per cent) or were unsure (13 per cent). Just over one quarter (26 per cent) expected their condition to stay the same and just nine per cent expected it to improve.





2.2.3 Severity/impact

EuroQol's EQ-5D-3L measurement of health was used to assess the severity of the reported conditions.²² Following this method, claimants were asked to indicate the impact of their condition on five key areas, listed below, by indicating whether they had 'no problems', 'some/moderate problems', or 'extreme problems /inability'. These areas were:

- Mobility (ability to walk about);
- Self-care (ability to wash and dress);
- Ability to perform usual activities (housework or family or leisure activities);
- Levels of pain or discomfort; and
- Levels of anxiety and depression.

²¹ A full breakdown of conditions is included in the Technical Appendix.

²² © EuroQol Research Foundation. EQ-5D[™] is a trade mark of the EuroQol Research Foundation

Responses to these questions were then used to calculate an overall health-related quality of life score, or 'health score' as it will be referred to hereafter. This health score is first explored here, while responses to each individual area are explored further in Chapter 3.

The calculation works by assigning all individuals a score of one and then subtracting a certain amount from this each time some level of difficulty is reported in one of the five areas. The greater the difficulty, the greater the subtraction; so that severity increases the closer the score is to zero (or negative value).

For the purposes of the analysis, the scores reported by claimants have been grouped into three bands:

- Moderate (score: 0.51-1) 24 per cent
- Poor (score: 0.26-0.5) 28 per cent
- Very poor (score: <0-0.25) 47 per cent

Looking at the derived health score, the average reported health score among claimants was 0.34, with the majority (75 per cent) assigned a score of 0.5 or below. By comparison, the average health score reported among the UK population is 0.83.²³ The scores among claimants ranged from -0.07 to 1.

2.2.4 Subgroup analysis

Demographics

The prevalence of health conditions varied a considerable amount among different demographic groups. For example, the proportion that reported experiencing stress or anxiety decreased with age (34 per cent of those aged 18-24 and 33 per cent of those aged 25-49 reported suffering from such conditions versus 21 per cent of those aged 50+). Conversely, the proportions that reported musculoskeletal conditions increased with age (25 per cent of those aged 18-24 reported such conditions, versus 39 per cent of those aged 25-49 and 69 per cent of those aged 50+). This increase in prevalence by age was also evident when looking at long-term conditions that affect major organs and the whole body (38 per cent of those aged 18-24 reported such conditions, versus 49 per cent of those aged 25-49 and 72 per cent of those aged 50+).

Health condition

There were correlations between different aspects of claimants' health conditions (such as condition type, severity or health score, history and prognosis).²⁴ For example:

²³ Janssen B., Szende A. (2014) Population Norms for the EQ-5D. In: Szende A., Janssen B., Cabases J. (eds) Self-Reported Population Health: An International Perspective based on EQ-5D. Springer, Dordrecht

²⁴ In the context of this research, prognosis is broader than the DWP definition and refers to the following: whether the condition fluctuates, how long the condition is expected to last and whether it is expected to improve in that time. Respondents were asked about these three factors during the interview.

- Prognosis tends to worsen as the health score deteriorates: 68 per cent of those with very poor scores reported that they expected their condition to get worse versus 47 per cent of those with poor scores and 28 per cent of those with moderate scores. Conversely, those with moderate health scores were more likely to report that their condition would stay the same (40 per cent versus 26 per cent on average) or improve (17 per cent versus 9 per cent on average).
- Health scores tended to deteriorate the later in life that the claimant's condition began. For example, 65 per cent of those with a very poor health score reported that their condition began during adulthood, versus 49 per cent of those with a poor score and 47 per cent of those with a moderate score. On the other hand, those who reported that their condition would improve over time were more likely to say that it had developed during adulthood (68 per cent versus 56 per cent on average) while those who reported that their condition would stay the same were more likely to say that it had developed at birth (26 per cent versus 16 percent on average) or during childhood (21 per cent versus 14 percent on average).
- The incidence of some conditions increased with the severity of the health score whereas for others, it decreased. For example, as shown in Table 2.5, musculoskeletal conditions were reported by 29% of those with a moderate health score, 41% of those with a poor health score and 70% of those with a very poor health score. Conversely, as show in Table 2.6 overleaf, conditions related to Asperger's or autism were reported by 13% of those with a moderate health score, 12% of those with a poor health score and 4% of those with a very poor health score.

	ŀ	Health score		
Condition	Moderate	Poor	Very poor	
Musculoskeletal conditions	*29%	*41%	*70%	
Long-term conditions that affect major organs or the whole body	*44%	*50%	*72%	
Depression	*28%	36%	*42%	
Diabetes	*7%	*9%	*17%	

Table 2.5: Examples of increasing prevalence of conditions by health score

Base – all who agreed to disclose their condition: Moderate (966); poor (574); very poor (462) *denotes where figures are significantly different to the average

	Health score		
Condition	Moderate	Poor	Very poor
Asperger's/Autism	*13%	*12%	*4%
Learning difficulties	*12%	8%	*5%
Learning disabilities ²⁵	*13%	*15%	*6%
Psychotic disorder or schizophrenia	*13%	*13%	*8%
Bipolar disorder	88%	4%	*3%

Table 2.6: Examples of decreasing prevalence of conditions by health score

Base – all who agreed to disclose their condition: Moderate (966); poor (574); very poor (462) *denotes where figures are significantly different to the average

Looking at mental health conditions versus other conditions, results suggest that mental health conditions are more difficult to predict: those who reported these conditions were more likely to say that the condition fluctuates (72 per cent versus 66 per cent on average) and were less sure how long their condition will last (23 per cent said they were unsure versus 17 per cent on average).

2.3 Employment history

This section considers the employment history of claimants, covering the extent to which claimants were currently working or volunteering; when, if ever, claimants last worked or volunteered; and what hours claimants had worked in their most recent employment.

2.3.1 History with paid work

Although most claimants (72 per cent) had some previous experience of paid work, claimants tended to be a long way from the labour market. Only two-fifths (39 per cent) had consistently been in paid work prior to their claim, a quarter (25 per cent) had never been in paid work, and those who had worked before had typically done so five or more years ago (30 per cent between five and 15 years ago, and 19 per cent more than 15 years ago – Figure 2.6).

²⁵ Learning disabilities are distinct from learning difficulties. Learning difficulties cover conditions such as dyslexia, dyspraxia and ADHD whereas learning disabilities relate more to individuals who may need care and support with day-to-day activities such as washing, dressing, cooking, leaving the house and communicating. For further information, please visit the Mencap website: <u>https://www.mencap.org.uk/learning-disability-explained</u>

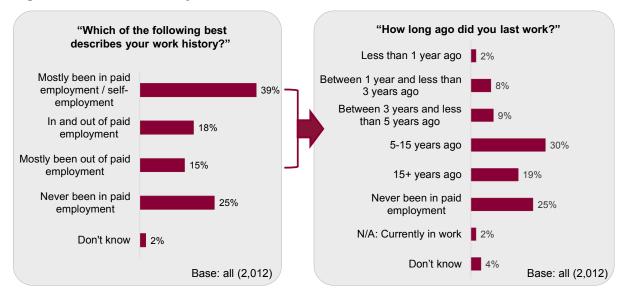


Figure 2.6: Work history and when last worked

Most (62 per cent) of those who had been in paid work before had been in full-time paid work (more than 30 hours per week). Longer part-time hours were slightly more common than shorter part-time hours; approaching one-fifth (17 per cent) had been in part-time paid work for between 16 and 30 hours per week, while 12 per cent had been in part-time paid work for up to 15 hours per week. A smaller group (six per cent) had been either in self-employed paid work or starting their own business.

A very small minority (2 per cent) were in work at the time of the interview, this group is explored in greater detail in section 4.1.1.

2.3.2 Subgroup analysis of employment history

Demographics

Those aged 18-24 were far less likely to have ever been in paid employment prior to their claim (21 per cent of 18-24 year olds, versus 72 per cent overall); this might reflect the qualitative findings regarding younger claimants' reported difficulties with the transition from a relatively well-supported school/college environment to relatively unsupported working/adult life (see section 3.1.3).

Those aged 18-24 were also more likely to have been in part-time employment (59 per cent of 18-24 year olds versus 29 per cent overall) and less likely to have been in full-time employment (31 per cent of 18-24 year olds versus 62 per cent overall).

Health condition

Those with fluctuating conditions were more likely to have some experience of paid employment (76 per cent versus 64 per cent of those with non-fluctuating conditions), perhaps indicating the ability to work during an improvement in their condition.

Those with mental health conditions were more likely to have ever been in paid employment (79 per cent versus 65 per without a mental health condition), but also more likely to have been in and out of paid employment (24 per cent versus 11 per cent without a mental health condition), suggesting that claimants with mental health conditions were able to enter work, but struggled to maintain employment consistently

over time. This is supported by the fact that mental health conditions are more likely to fluctuate (72 per cent versus 59 per cent of claimants without a mental health condition – see section 2.2.4).

Those with any mental health condition were also slightly less likely to have done full-time paid work as their most recent role (60 per cent versus 65 per cent of those with no mental health condition).

Benefits history

As would be expected, distance from paid work increased with time on out of work benefits. A third (33 per cent) of those on out of work benefits for over 10 years had never been in paid employment (versus 25 per cent overall), suggesting that members of this group are more likely to have life-long conditions that have always posed a barrier to working. Other evidence supports this hypothesis: there were higher incidences of claimants having had their health condition since birth among those who had never been in paid employment (47 per cent of whom had had their health condition since birth) and among those who had been on out of work benefits for over 10 years (22 per cent of whom had had their health condition since birth) than among claimants overall (16 per cent of whom had had their health condition since birth).

Employment and Support Allowance (ESA) and Universal Credit (UC)

There was no clear pattern of difference in history with paid work, between ESA and UC claimants.²⁶

Other subgroups

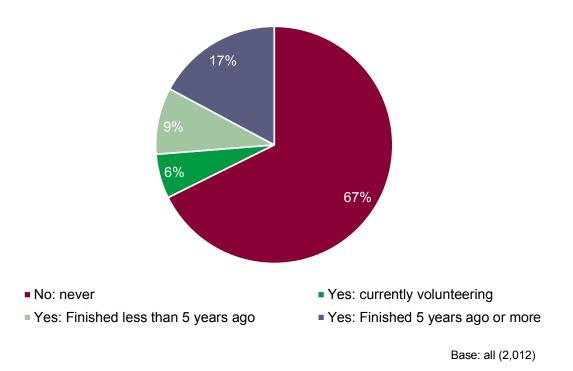
Those with higher qualifications and more advanced digital skills (confident or expert level) were more likely to have ever been in paid employment (95 per cent of those with higher qualifications and 82 per cent of those with more advanced digital skills, versus 72 per cent overall), indicating that it is not just health barriers but also skills-related barriers and enablers which influence likelihood to have worked. Equally, it is possible that claimants acquired or improved upon their digital skills whilst in employment.

2.3.3 History with voluntary work

Most claimants (67 per cent) had never undertaken voluntary work, although a significant minority (32 per cent) had. Mostly this was five or more years ago (17 per cent), however six per cent reported that they were currently engaged in such activities (Figure 2.7).

²⁶ Such patterns as exist were contradictory and difficult to interpret.





"Have you ever undertaken voluntary work?"

Claimants who were in voluntary work at the time of the survey are described in greater detail in section 4.2.1.

2.4 Routes into the support group

This section considers the events or circumstances that led to claimants' entering the ESA Support Group or UC equivalent. It focuses exclusively on the findings from the in-depth interviews.

The in-depth interviews revealed three types of circumstances that led to people entering the Support Group or equivalent UC group, two routes among those who had experience of employment and a third among those who did not:

• **Experience of employment (1):** this group tended to have left employment following a specific unpredictable incident (e.g. a heart attack, being assaulted, experiencing depression following a bereavement or relationship breakdown). This was common among individuals who were undertaking particularly physical work, and often, these individuals were involuntarily forced to leave work after reportedly being advised to leave, or retire, by their employer, following the onset of ill-health. Examples of where this happened included a ground worker, a chef, a postal worker, and a prison officer. These individuals reported that they were unable to undertake their duties because of their health condition but there was no offer of taking up a different position within the organisation, even when this was requested by the individual. Individuals in this group tended to have long working histories, often for the same employer,

but for some there was no help from their employer to return to their role once their health had become more manageable. Some individuals reported feeling 'managed out' of their roles by Occupational Health professionals.

'There was no support mechanism around ... if it wasn't for my family I would have gone off the rails.'

(Male, 35-44, in-depth interviews)

• Experience of employment (2): these claimants tended to have left employment due to a gradual deterioration in their health conditions over time (e.g. asthma, diabetes, depression, substance dependency or heart disease). Some felt their employer had failed to help them stay in or return to work; and (as above) some felt 'managed out' of their roles by Occupational Health professionals. Others had experienced lengthy periods of employment, typically in the same industry, or had a skilled trade (e.g. construction, catering), but now felt their condition had rendered them unsuitable for their chosen industry.

'I would be a H&S liability, I couldn't help with machinery or even lifting a plank of wood.'

(Male, 45-54, in-depth interviews)

 Little or no experience of employment: some younger individuals aged 18-35 years had entered employment for a brief period, often on a temporary or zero-hours contract basis, but had found it too challenging to continue. Examples include an individual with a mental health condition who had struggled to hold down a job in a factory, an individual with autism who had done a short period of zero-hours cleaning work, and an individual with a mental health condition who had previously held a retail position and also undertaken voluntary work in a charity shop. One was asked to leave and the others chose to (either because they felt bullied and mocked by other employees, or because they were struggling to manage their mental health).

'They said they didn't want me anymore...I was too slow at taking orders...needing to be told what to do.'

(Male, 25-34, in-depth interviews)

Despite these experiences, they were usually very enthusiastic about working and most were actively looking for employment. Others in this group of individuals, however, had been claiming benefits ever since leaving full-time education; and this was also the case for those with appointees, who tended to say that the individual's health condition or disability (often present from birth) prevented them from working.

3 Individuals' daily lives

This chapter discusses individuals' daily lives, including typical day-today activities. It examines how claimants manage their health conditions, and the impact these have on what they can do. It also discusses any support that they are currently receiving; and their receipt of, and uses for, Personal Independence Payment (PIP) or Disability Living Allowance (DLA). The findings reported in this chapter are drawn from both the qualitative and the quantitative strands of the research. The source used is indicated throughout.

3.1 Day-to-day impact of health condition(s)

The in-depth interviews found that claimants' daily lives were often shaped by the severity and impact of their health condition(s). Those whose conditions were more manageable, were able to fit their health needs into a routine alongside socialising, attending college or community groups or undertaking hobbies; while, at the other extreme, a few individuals whose conditions were harder to manage, talked about their daily lives being dominated by health care needs, coping with pain, and medical appointments.

'I hate it. I'm trapped inside anxiety. I feel like I can't do anything properly, go anywhere or meet people – do what normal people do.'

(Female, 25-34, in-depth interviews)

'I have a couple of friends who drag me out for a coffee every couple of months – beyond that it is my sister, husband and son It takes me about 10 minutes to walk across the road to the park – I have to use a stick.'

(Female, 45-54, in-depth interviews)

Some claimants felt frustrated or isolated, often due to difficulty in leaving the house because of pain, mobility issues, mental health conditions, lack of money or, for individuals with hearing impairments, communication barriers.

A few younger claimants reported having limited support networks and often described their lives as 'chaotic' due to mental health conditions, homelessness or insecure housing and/or substance abuse. Several of these claimants said that, day to day, they had little to do and would sometimes isolate themselves due to mental health problems and not wanting to mix with others.

'I just need to sort out an address. I think I am scared to live on my own ... it has got worse [recently]. I have stabbed myself a few times [again] ... I was so angry and just want to beat up everyone.'

(Male, 25-34, in-depth interviews)

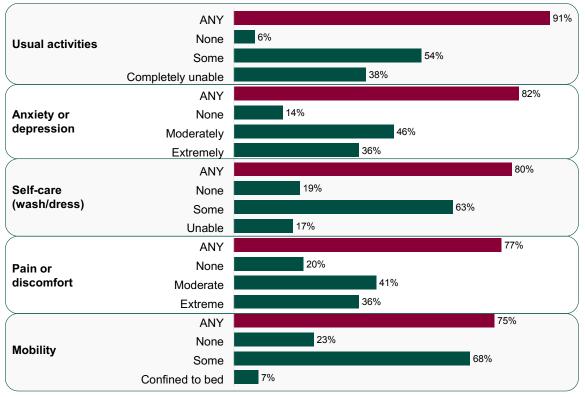
Nearly all of the peer-to-peer interview participants were involved in regular activities such as a small amount of part time work, volunteering or attending a support group. This is perhaps to be expected as they had been recruited to participate in the peer interviews via voluntary organisations. Some were very much dependent on family, for example to help them travel to these commitments, while others were very independent. One individual, however, reported that most of their time was taken up in caring for a relative.

As discussed in Chapter 2, EuroQol's EQ-5D-3L measurement of health was used in order to assess the severity of the reported conditions.²⁷ Claimants were asked to indicate the impact of their condition on five key areas, listed below, by indicating whether they had 'no problems', 'some/moderate problems', or 'extreme problems/ inability'. These areas were:

- Mobility (ability to walk about);
- Self-care (ability to wash and dress);
- Ability to perform usual activities (housework or family or leisure activities);
- Levels of pain or discomfort; and
- Levels of anxiety and depression.

As well as using these responses to calculate a health-related quality of life score ('health score' – see section 2.2.3) they can also be looked at individually as an indicator of impacts on daily life. These impacts are described in Figure 3.1.

Figure 3.1: Impact of health condition on daily lives



Reported difficulties with ...:

Base: all (2,012)

²⁷ © EuroQol Research Foundation. EQ-5D[™] is a trade mark of the EuroQol Research Foundation

This shows that the majority of claimants reported at least some difficulty in all five areas, with impacts on the ability to perform usual activities, anxiety or depression and self-care emerging as the most prevalent three (reported by 91 per cent, 82 per cent and 80 per cent respectively). Just over a third of claimants reported extreme issues with pain or discomfort, performing usual activities and anxiety or depression (36 per cent, 38 per cent and 36 per cent respectively). In contrast, extreme issues with self-care and mobility were less common (17 per cent and seven per cent respectively).

3.2 Volunteering activities

In the survey, six per cent of claimants reported that they were engaged in voluntary work. Those more likely to be undertaking voluntary work are explored in more detail in section 4.2.1.

Looking at the qualitative findings from the in-depth interviews, most respondents explained that their volunteering commitments were fairly ad hoc and depended on how they were feeling. For example, they might spend around two hours a week helping at a charity shop, or a hostel, giving IT lessons or giving advice for RNIB.

'It's not full on or anything, more of a step in to see what's out there.'

(Female, 25-34, in-depth interviews)

That said, a few older individuals who had been out of work for less than three years were volunteering on a full time or regular part time basis, at a range of different organisations such as Citizens Advice, MIND and local disability awareness groups.

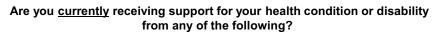
Most of the peer-to-peer interview participants were involved in volunteering or had been recently. Respondents perceived a range of benefits from participating in voluntary work. These included building confidence in taking part in something outside of their home and circle of friends, enhanced understanding of the kind of support other people with disabilities receive and a general sense of fulfilment. This voluntary work was not necessarily seen as means of moving closer to paid work.

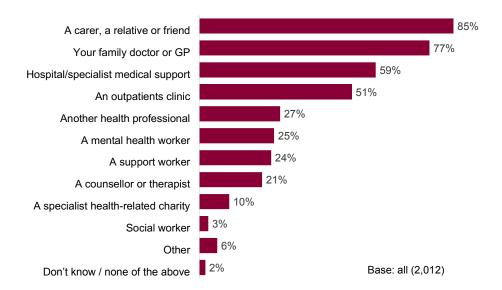
3.3 Health-related support currently received

In the survey, claimants were asked whether they were receiving support for their health condition. Responses were prompted with a list, shown in Figure 3.2.²⁸

²⁸ The 'social worker' option was not part of the original list, but came out spontaneously via 'other'.

Figure 3.2: Health-related support





Nearly all (97 per cent) reported that they were receiving some form of support for their condition and the majority (89 per cent) reported receiving multiple forms of support (equating to an average of 3.9 forms of support per person). Claimants predominantly received support from a carer, relative or friend (85 per cent) or, in the medical profession, from a family doctor or GP (77 per cent). This was often alongside other forms of support.

Six per cent reported that they **only** received support from a carer, relative or friend and nine per cent reported that they **only** received support from a carer, relative, friend or GP. Receipt of support exclusively from a carer, relative or friend, although uncommon, was higher among those with less severe conditions:

- Conditions that were expected to stay the same (10 per cent).
- Those who reported having a single condition (13 per cent).
- Those with a moderate health score (8 per cent versus 4 per cent of those with a very poor score).
- Conditions that were not related to mental health (7 per cent of those with no mental health condition versus 4 per cent of those with any mental health condition).

It was also slightly higher among:

- Younger claimants i.e. those aged 18-24 (10 per cent)
- Males (8 per cent).

A key finding that emerged from the qualitative element was that many of those with a mental health condition were not receiving mental-health related support. Several of the in-depth interview participants felt they needed someone to talk to for emotional support while others said they would have liked previous counselling or psychiatric help to have continued. The lack of continuous therapeutic sessions for mental health problems was also a prominent theme in many of the focus groups. For example, several young participants (aged between 18 and 30) with mental health conditions expressed frustration at therapy sessions stopping after six weeks and having to

go on waiting lists again for the next group of sessions. They wanted help building self-esteem and routines and felt this would help improve their confidence.

The quantitative data is consistent with this finding; although the proportion receiving help from a mental health worker or counsellor/therapist increased among those with a mental health condition (37 per cent and 27 per cent respectively, compared with 10 per cent and 15 per cent respectively among those with no mental health condition) this still leaves 53 per cent not receiving support from either.

Qualitatively, the in-depth interviews found some claimants did not seek out, or take up, support with their condition because they felt there was a stigma attached to asking for help. They felt that morally they should rely on family or friends rather than taking 'handouts' from external agencies. Many felt ashamed or talked about the stigma of being in a group that took government support rather than being part of society that is 'contributing' by working. These individuals often had not considered asking for additional help (outside of that being offered by close friends or family) due to feelings of guilt or embarrassment.

Their reliance on informal support from family or friends meant that they were less aware of the specialist support available to them. Sometimes the individuals who were reliant on family and friends noted that a drawback of this support was that their family and friends did not fully understand their health condition.

'They [family] will listen, but it is hard because I don't think they quite understand [the health condition]. I'm not sure he [my partner] understands all of it ... I know he tries his best but I don't think he fully gets it.'

(Female, 18-24, in-depth interviews)

When asked what other health-related support they would ideally have, many found it difficult to identify anything other than what they had tried or been offered before – such as a day centre or respite care (for social interaction); the resumption of previous counselling or psychiatric help; or financial support to help with costs associated with wider concerns, such as housing.

The qualitative in-depth interviews also uncovered some hesitancy to take up support from local organisations where individuals thought these organisations might be closed down or have their funding withdrawn, as they found it difficult to invest emotionally in relationships that they thought might end. Young people aged 18-24 found it particularly difficult to build trust, and had often lacked support beyond their immediate family, since leaving full-time education.

3.3.1 Subgroup analysis on health related support

Health condition

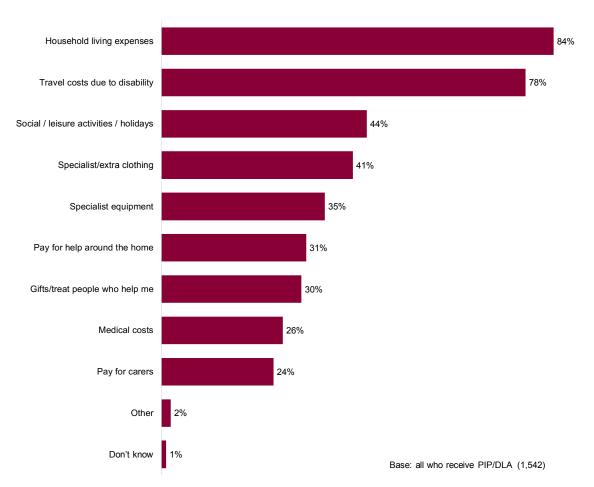
There was some variation in the level and type of health-related support currently received, by condition type and prognosis. For example, those with multiple conditions reported that they were receiving more forms of support on average than those with single conditions (4 versus 3.2) as did those who thought their condition would get worse (4.1 versus 3.6 stay the same and 3.5 improve) and those with a very poor health score (4.1 versus 3.8 poor and 3.4 moderate). These differences are more clearly marked among some forms of support that others. For example, those whose condition is likely to last for the rest of their life were more likely to report receiving

support from a carer, relative or friend (88 per cent) than claimants on average (85 per cent) and claimants who thought their health condition would be resolved in up to six years (54 per cent).

3.4 Receiving PIP or DLA

In the survey, the majority (77 per cent) reported receiving Personal Independence Payment (PIP) or Disability Living Allowance (DLA) alongside their ESA/UC claim. PIP and DLA each consist of a mobility and a daily living component. Claimants reported using these for a variety of purposes, outlined in Figure 3.3.

Figure 3.3: Uses of PIP/DLA



"In which of the following ways do you use your PIP / DLA payment?"

As this shows, PIP/DLA is most commonly spent on household living expenses and disability-related travel costs (84 per cent and 78 per cent respectively). Although much less prevalent, other uses of PIP and DLA are also fairly common; for example, social/leisure activities or holidays (44 per cent); specialist/extra clothing (41 per cent); and specialist equipment (35 per cent).

In the in-depth interviews, those receiving PIP or DLA felt that it made a significant difference to their quality of life. The mobility component enabled people to leave the house, by funding taxis, cars (through the Motability Scheme) or family members' petrol.

'The car is a godsend. When I have the car, it doesn't matter what the weather is we can go out down to the shopping centre. We're not going to be stuck in the house. I don't know how I'd manage if I didn't have a car.'

(Male, 18-24, in-depth interviews)

The daily living component was put to more diverse uses: to fund specialist equipment such as wheelchairs or electronics with audio description technology; specially-adapted common items such as shoes or clothing; to pay relatives or friends who provided informal care; or – to a lesser extent – activities to alleviate social isolation.

'Clothes are really difficult to find when you are sitting in a wheelchair ... all too big so you have to have them adjusted ... so things like [DLA] makes a difference to whether you can afford to do that or not.'

(Female, 55-65, in-depth interviews)

'I couldn't afford to pay [my sister who is my carer] anything if I only had the ESA money – this is where the PIP comes in handy, it just gives me that bit extra; I'd struggle without it.'

(Female, 45-54, in-depth interviews)

4 Attitudes towards employment

This chapter examines how claimants feel about paid work, how likely they think they are to work and at what point in the future, and what barriers they perceive to seeking employment. It also covers claimants' attitudes towards voluntary work. Claimants with a terminal illness who responded to the survey (8 per cent of the sample) were not asked questions about these topics, and are excluded from the survey findings in this chapter.

4.1 Closeness to paid work

The survey asked claimants several questions about how they felt about working and whether, and when, they thought they might be able to do paid work in future. Using the responses to these questions, we calculated each claimant's self-assessed 'closeness to work', in terms of whether they felt they could undertake paid work, and at what point. Claimants were then grouped into:

- Those who are currently in paid work;
- Those who felt they could work in the near future (within two years of the survey);
- Those who felt they could work in the further future (more than two years from the point of the survey);
- Those who felt their health rules out ever working in future;
- Those who did not completely rule out work on the grounds of their health, but nevertheless indicated that it was unlikely; and
- Those did not know whether they could work in the future.

Further detail on how these groups were derived can be found in the Technical Appendix.

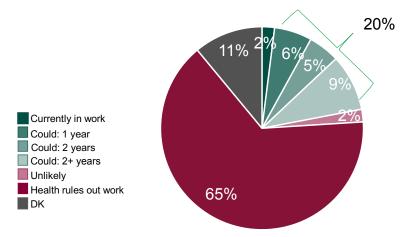
Two per cent of claimants were already undertaking some paid work at the time of the survey (Figure 4.1).

A further one in five claimants (20 per cent) felt paid work could be possible in future. There was a fairly even split between those who felt they might be able to work within the next two years, and those who felt they might be able to work in the further future: 11 per cent of all claimants (except those with a terminal illness) said they might be able to work within the next two years and nine per cent felt they might be able to work in more than two years' time. Those who felt closest to being able to work included four per cent of claimants who thought they could work now if the right job was available and with the right support.

The majority of claimants (65 per cent), however, ruled out work in the future on health grounds (65 per cent of all claimants). A further two per cent did not completely rule out work on the grounds of their health, but nevertheless indicated that it was unlikely.

Eleven per cent of claimants did not know whether they could work in the future. This group were more likely to have a mental health condition (70 per cent compared to 52 per cent of all claimants). They were also more likely to say they thought their condition would improve in the future (22 per cent compared to eight per cent of all claimants).

Figure 4.1: Perceived closeness to paid work across the ESA Support Group/ equivalent UC group



Base: all excl. terminally ill and those who could not be assigned a segment²⁹ (1,814)

As shown in Figure 4.2, among those currently unemployed who felt they might be able to enter work in the future:

- Over half were interested in part-time work (56 per cent). Two-fifths (40 per cent) were interested in working up to 15 hours per week, i.e. close to the current permitted work rules and 15 per cent were interested in working between 16 and 30 hours per week.³⁰ This sums to 56 per cent due to rounding.
- A significant minority (30 per cent) were interested in full-time paid work and a further 12% were interested in self-employment.

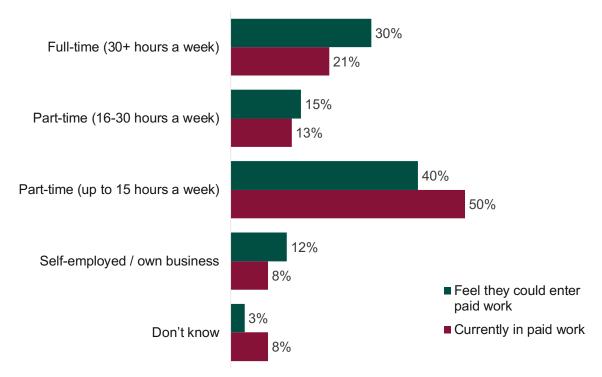
²⁹ Twenty-two individuals could not be assigned a segment because they did not give a sufficient level of response to the questions about perceived barriers and support offers (repeatedly selecting a non-response option, such as 'neither agree nor disagree', 'don't know' or 'refused'). See Annex A: Detailed methodology.

³⁰ People claiming ESA can do permitted work without it affecting their benefit. It is permitted work if: (a) claimants earn up to £125.50 a week; and (b) claimants work less than 16 hours a week. In UC claimants who have a health condition or disability and have had their Work Capability Assessment receive a Work Allowance: those who receive money to help with their housing costs can earn up to £287 per month without it affecting their UC payment; and those who do not receive help with their housing costs can earn up to £503 per month before earnings are deducted from their benefit award. UC claimants are not restricted on the number of hours they work to make up those earnings.

Among those currently employed:

- Almost two-thirds were interested in part-time work (63 per cent). Half (50 per cent) were interested in working up to 15 hours per week and a further 13 per cent were interested in working between 16 and 30 hours per week.
- A significant minority (21 per cent) were interested in full-time paid work and a further 8% were interested in self-employment.

Figure 4.2: Hours of work claimants were interested in



Base: all who felt they could undertake paid work in future (389), all those in paid work (42)

Claimants who felt they would like to do full-time work in future were more likely to:

- Have a better health outlook: 49 per cent of those interested in work and who thought their condition would improve were interested in working full-time.
- **Be male:** 38 per cent of male claimants who were interested in work, were interested in working full-time, compared to 19 per cent of female claimants who were interested in work.
- Have a mental health condition: 37 per cent of claimants with a mental health condition who were interested in work, were interested in working full-time.

There was no clear pattern of difference between ESA and UC claimants.³¹

In the in-depth interviews, part-time work was generally thought of as a more realistic goal by those who felt that their health prevented them from working full-time. This included both people who felt they could return to work in the near future, and those who were considering it in the longer term. In both cases, part-time work was viewed as a way to achieve something even though working full-time was not possible.

³¹ Such patterns as exist were contradictory and difficult to interpret.

Those who ruled out full-time work often did so because of their age or because of the expected progression of their health condition. This is supported by the survey findings: those aged 50+ were more likely to be interested in working part-time, for between 16 and 30 hours per week (23 per cent, compared with 15 per cent on average); while those who expected their condition to stay the same or get worse were more likely to be interested in part-time work of up to 15 hours per week (52 per cent of those expecting no change and 41 per cent of those expecting a deterioration compared with 25 per cent of those who expected their condition to improve).

In the next sections, we profile the following groups of claimants, defined by their closeness to work:

- Those currently in paid work.
- Those who felt they might be able to do paid work in the near future (within the next two years).
- Those who felt they might be able to do paid work in the further future (more than two years).
- Those who felt their health rules out ever doing paid work.
- Those who had ruled out work as an option, for other reasons.

This analysis showed that there were three notable overall trends (illustrated in Figure 4.3):

- The likelihood of claimants feeling that they might be able to do paid work decreased with age.
- Claimants with less severe health conditions (higher health scores) were more likely to feel that they could undertake paid work in the near future and those with very poor scores were more likely to feel that they could work either in the further future or not at all.
- Claimants who felt they could undertake paid work in the near future were more likely to have received benefits for less than one year.

Again, there was no clear pattern of difference between ESA and UC claimants.³²

³² Such patterns as exist were contradictory and difficult to interpret.

Figure 4.3: Relationship between closeness to paid work and claimants' age, health score and time on out-of-work benefits Base = Those who felt their health rules out work, 1,134 53%* Time on out of work benefits *50% *42% *44% *52% *1% 7% Health rules out work 28% 19%* 25-49yrs 18-24yrs 1-10yrs >10yrs 50+yrs Moderate Poor <1yr Very poor Health Health score Age -) -) Base = Those who felt they could enter work beyond two years, by closeness to work variable, 170 2 years Time on out of work benefits *69% *26% 38%* 3% *25% *64% 11% 33% 29% Could work: later than 1-10yrs >10yrs 8-24yrs 25-49yrs <1yr Moderate Poor 50+yrs Very poor Health score Health Age Base = Those who felt they could work in the next two years, by closeness to work variable, 219 Could work in the near future *10% Time on out of work benefits *73% *13% *14% *61% *25% 40%* 32% 28%* >10yrs 1-10yrs 18-24yrs 25-49yrs 50+yrs <1yr Poor Moderate Very poor Health Health score -) -) Age

*denotes where figures are significantly different to the average across all claimants; arrows signify if they are higher or lower than the average.

4.1.1 Claimants who were currently in work

Two per cent of claimants were currently undertaking some sort of paid work. This group comprised only 42 respondents (one Universal Credit LCWRA claimant, and 41 ESA Support Group claimants), so findings should be treated with caution. They were generally more likely to be in part-time paid work and predominantly working 15 hours or less, i.e. they could be doing permitted work. Most said they were already doing the amount of paid work that they wanted to do, or felt capable of. Most wanted to work part time (as discussed in section 4.1).

Claimants who said they were currently undertaking some sort of paid work (two per cent) all had prior experience of paid work and were more likely to have mostly been in paid employment in the past (65 versus 39 per cent of all claimants). They were also more qualified and digitally engaged: 66 per cent had a Level 2 qualification versus 29 per cent of claimants overall; three quarters had internet at home versus 59 per cent of claimants overall; and 37 per cent were confident/expert internet users versus 22 per cent of claimants overall.

Those currently in work also tended to have more stable accommodation and fewer caring responsibilities, for example owning their home (40 per cent versus an average of 23 per cent) and living without dependent children (97 per cent versus 83 per cent on average). As might be expected, they also had a better health score and prognosis: 46 per cent had a moderate health score versus 24 per cent of all claimants; 27 per cent expected their condition to improve and 42 per cent stay the same, versus 8 per cent and 24 per cent saying this on average.

4.1.2 Claimants who felt they could work within two years

This group made up one in nine (11 per cent) of claimants.³³

These claimants were more likely to be younger, male, with less severe health conditions and/or to have been out of paid work for less time. They were also more likely to be involved in voluntary work.

This group contained a considerably higher proportion of 18-24 year olds than the average amongst all claimants (14 per cent compared to 7 per cent for claimants overall). There was also a higher proportion of men in this group (59 per cent versus 49 per cent for claimants overall).

This group tended to have better health scores. For example, 40 per cent had a moderate score, compared to only 29 per cent of those who felt they could work in the further future and 19 per cent of those who felt they could not work at all. This aligns with the in-depth interviews, which found that claimants who felt they could work in the near future tended to have conditions with symptoms that were easier to manage, including a few who were recovering from or waiting for operations, with an expectation of their health improving as a result.

Claimants who felt they could work in the near future were more likely to be short-term benefit claimants. Ten per cent had been receiving out of work benefits for less than

³³ Excluding the terminally ill and those who could not be assigned a segment. Twenty-two individuals could not be assigned a segment because they did not give a sufficient level of response to the questions about perceived barriers and support offers (repeatedly selecting a non-response option, such as 'neither agree nor disagree', 'don't know' or 'refused'). See Annex A: Detailed methodology.

one year, compared with three per cent of claimants overall, and only 13 per cent had received benefits for over ten years compared to 36 per cent overall.

Those who felt they could undertake paid work in the near future were also considerably more likely to be involved in volunteering according to the survey results, with 19 per cent undertaking voluntary work at the time of the survey versus six per cent of those who thought they could work in the further future, and five per cent of those who were unlikely to work again. We look at the relationship between paid work and volunteering more closely in section 4.2.2.

As might be expected, those who felt they could work in the near future were also more likely to have undertaken paid work in the recent past, compared to claimants overall. Eight per cent had worked less than one year ago compared to two per cent overall.

The in-depth interviews further illuminate this group's relationship with paid work and identified two key groups who felt they could return to work in the near future:

• The first group had often worked in the past. Some were determined to work, and a strong work ethic was part of their identity. They were generally in their late twenties or older, and doing some sort of work-related activity at the time of the interview, such as volunteering or doing ad-hoc temporary work for example as a teaching assistant or in self-employment e.g. speech writing or making home deliveries.

'I have worked all my life and [were I to] stay in the home I would probably go mentally ill ... it is better to be with people and involved.'

(Male, 45-54, in-depth interviews)

• The second group were young people who had limited work experience. They tended to be in their early twenties and were very enthusiastic about work but not sure of their options or potential career paths, or what they were qualified for. This had led a few to consider working in the same role as an influential person in their life, such as a support worker. Another individual with autism had a clear idea of the type of position he wanted to go into (warehouse work, which he felt would suit his needs) and had been trying to find a suitable vacancy locally, whilst another was keen to run his own business but did not know where to start.

4.1.3 Claimants who felt they could work in more than two years' time

This group made up one in eleven (9 per cent) of claimants.³⁴

Claimants who felt they might be able to do paid work in the further future (more than two years from the point of the survey) were in relatively poorer health and were slightly more likely to have been out of work for longer than those who thought they could work in the near future.

³⁴ Excluding the terminally ill and those who could not be assigned a segment. Twenty-two individuals could not be assigned a segment because they did not give a sufficient level of response to the questions about perceived barriers and support offers (repeatedly selecting a non-response option, such as 'neither agree nor disagree', 'don't know' or 'refused'). See Annex A: Detailed methodology.

Nearly two in five claimants in this group (38 per cent) had a very poor health score. While this is slightly better than the average for all claimants (47 per cent had a very poor health score), it shows that this group are likely to be in poorer health than those who felt they could work in the near future (of whom only 28 per cent had a very poor health score). This group were also slightly more likely to have multiple health conditions than claimants as a whole (93 per cent versus 87 per cent on average for all claimants).

This is in line with findings from the in-depth interviews, which showed that those who felt their return to work would be at a later stage tended to have conditions with more complex symptoms. They typically felt that they needed to make significant progress with their health (for example, needing to improve their mental health so that they could leave the house; improving their ability to manage pain, or requiring surgery) before thinking seriously about what kinds of paid work might be possible.

The survey found that this group were likely to have been out of work for longer, compared to those who felt they could undertake paid work in the near future. One in four (26 per cent) had been receiving out of work benefits for over ten years, double the proportion reporting this among the group who felt they could work in the near future (13 per cent).

This group were predominantly aged between 25 and 49 years (64 per cent).

4.1.4 Claimants who felt their health rules out work

This group made up two thirds of claimants (65 per cent) and their characteristics are therefore closer to the ESA Support Group and Universal Credit LCWRA group as a whole.³⁵ They were considerably more likely to be older and have a worse health score than the claimants who could undertake paid work either in the near or further future.

Over half were over 50 years old (52 per cent, versus 28 per cent of the groups who felt that future paid work was possible). Only seven per cent were under 25 years old.

This group were also more likely to have a poorer health score. Over half had a very poor health score (53 per cent, versus 25 per cent of those who felt they could do paid work in the near future, and 38 per cent of those who felt they could work in the further future (Table 4.1).

³⁵ Excluding the terminally ill and those who could not be assigned a segment. Twenty-two individuals could not be assigned a segment because they did not give a sufficient level of response to the questions about perceived barriers and support offers (repeatedly selecting a non-response option, such as 'neither agree nor disagree', 'don't know' or 'refused'). See Annex A: Detailed methodology.

Health score	Could work in the near future	Could work: later than 2 years	Health rules out work	All Support Group (and equivalent) claimants
Very poor	28%	*38%	*53%	47%
Poor	32%	33%	28%	28%
Moderate	*40%	29%	*19%	24%

Table 4.1: Health scores and closeness to work

*denotes where figures are significantly different to the average across all Support Group (and equivalent) claimants

Base: Near future (219), Later (170), Health rules out work (1,134), All (2,012)

The in-depth interviews found that those who felt their health rules out work tended to have multiple physical conditions, often combined with a mental health condition that had deteriorated over time; and either expected their health to get worse in future or were unsure of what the future will bring. They either felt unable to work because of their health, or that work would upset the level of stability with their physical or mental health they had worked hard to achieve. Individuals over 50 years old often didn't consider work possible because they couldn't return to the same line of (often physical) work. Some felt their GP or the Department for Work and Pensions (DWP) had taken the view that they cannot work.

A few individuals who were interviewed (of all ages, not just those aged over 50) did express an interest in working but felt that they had no option to do so because they could not envisage any employer that would be able to accommodate their needs, e.g. regular breaks or time off for medical appointments. They had a range of different conditions including a visual impairment, degenerative arthritis, spinal injury and chronic pain.

'I would love to...If I had an option to go work now I would run to it but you know, I can't so, that's it... In this condition what could I do?'

(Male, 25-34, in-depth interviews)

The survey also found that these claimants were more than twice as likely to have left their last job more than ten years ago than those able to work in the near future (35 per cent versus 15 per cent). They were also more likely to have never worked before (30 per cent versus 19 per cent of those who could work in the further future and 21 per cent of those who felt they could work in the near future). This is likely to be related to the finding that this group were more likely to report that their condition had developed at birth (20 per cent versus 16 percent on average).

There are several other factors that place this group further from the labour market and distinct from those who felt they could undertake paid work in future:

• They were more than twice as likely to have no internet access than those who felt they could undertake paid work (25 per cent versus nine per cent of those who felt they could work in the further future, and ten per cent of those who felt they could work in the near future).

- They were twice as likely to say that they cannot, or struggle to use the internet (50 per cent versus 25 per cent who felt they could work in the further future, and 21 per cent of those who felt they could work in the near future).
- They were more likely to have no qualifications (41 per cent, versus 24 per cent of those who felt they could work in the further future and 13 per cent of those who felt they could work in the near future).

4.1.5 Claimants who had ruled out work as an option for other reasons

Two per cent of claimants (44 respondents in total) did not rule out work on health grounds, but nevertheless felt that they would not work again. There are no strong patterns to suggest their reason for ruling out work. It is likely that their health was still a factor, but was possibly not the only or biggest factor taken into account when they were considering the prospect of paid work in the future (hence they may have felt that the response 'My health condition/disability rules out work as an option now and in the future' was not an accurate portrayal of their position).

4.1.6 Motivations to work

In the in-depth interviews, claimants' motivations for working largely focused on work as a means to improve their personal wellbeing, or on the financial benefits.

Work was seen as a key way that some claimants could improve their wellbeing by boosting their confidence or self-esteem, by giving them a 'purpose' in life or by demonstrating that they had 'defeated' their condition. This was particularly the case among 36-49 year-olds who were very enthusiastic about working because having a strong work ethic was part of their personal identity. Similarly, for some, work was a way of getting out of the house and interacting with other people. This was particularly mentioned by those who felt work was a possibility in the longer-term. These were also all key reasons why some individuals had taken up voluntary work.

For those that had a financial motivation to work, this was sometimes about increasing their personal financial position, particularly among those that had been struggling financially since becoming unemployed. For others, the main motivation was that they wanted to be perceived as someone who contributes to society, as a worker/taxpayer rather than being stigmatised as a benefits claimant. Similarly, several peer-to-peer interview participants were very open in their dislike of being in the ESA Support Group. Specifically, they mentioned the associated stigma, that being on benefits felt 'intrusive' or that it made them feel different to their family.

To a lesser extent, some in-depth interview participants wanted to return to work in order to be a positive role model to their children, or so that they could help others.

4.2 Voluntary work and its relationship with paid work

As part of this research we asked claimants about whether they were currently, or had ever engaged in volunteering, or if they would be interested in volunteering in the future. This was partly to explore whether volunteering played a part in claimants' daily lives. It was also to examine how attitudes towards volunteering related to claimants' feelings about doing paid work in future. It was highlighted in the in-depth interviews and focus groups that volunteering is viewed by some as a potential 'stepping stone' towards paid work, although this is not always the case.

Using responses to three survey questions, claimants were categorised in terms of their closeness to voluntary work, as illustrated in Figure 4.4.³⁶

The findings for voluntary work were similar to those for paid work: a minority (six per cent) were volunteering at the time of the survey, and a fifth (19 per cent) felt it was a possibility in the future.

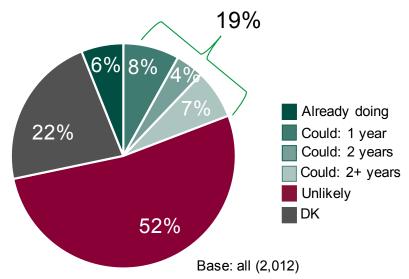


Figure 4.4: Closeness to voluntary work

Over half of all claimants (52 per cent), however, indicated voluntary work was unlikely, either because they were not interested, or they did not think it was an option for them.

The focus group findings suggested some reasons why claimants might not always be interested in voluntary work. In response to a presentation by a Disability Employment Advisor (DEA) from Jobcentre Plus (JCP) on the types of support and opportunities available, some claimants expressed scepticism about volunteering opportunities, as either being quite physically demanding and unsuitable for those with physical health conditions; or customer-facing, which they felt would not be suitable for those with mental health conditions. They were also aware that activities such as work experience and volunteering are popular and believed that, although these offers 'exists on paper, once you go there [e.g. to JCP] it's a different story'.

We will now profile those who were volunteering at the time of the survey, before considering what this means for the relationship between voluntary work and paid work among all claimants.

³⁶ See the Technical Appendix for an explanation of how these groups were derived.

4.2.1 Claimants who are currently volunteering

Those in voluntary work were more likely to be men and/or between 25 and 49 years old (63 per cent were male and 69 per cent were 25-49 year olds). Claimants aged 50+ were far less likely to be involved in voluntary work (23 per cent of volunteers were aged 50+ compared to 46 per cent of all claimants). Figure 4.5 illustrates their age, health and closeness to paid work. The arrows indicate where these characteristics are significantly different from the average for the whole claimant group.



Figure 4.5: Characteristics of claimants currently in voluntary work Currently in voluntary work

Base = Currently volunteering: 109

Like those in paid work, claimants who were currently volunteering were more likely to have a better health score and prognosis. They were more likely than claimants on average to have a moderate health score (46 per cent versus 24 per cent) and they were more likely to report that they expected their conditions to stay the same (41 per cent versus 24 per cent). However, unlike those in paid work, they were more likely to say their condition will last for the rest of their life (82 per cent versus 72 per cent of all claimants).

Those involved in volunteering were more likely to be living rent free, including in a relative's or friend's property and without dependent children. Over a quarter (27 per cent) lived rent-free versus the average of one tenth among all claimants, while nearly all lived without dependent children (93 per cent versus the average of 83 per cent among all claimants).

They were also more digitally engaged: 72 per cent had access to the internet at home which is 13 percentage points above the average among all claimants, and 35 per cent described themselves as confident or expert internet users versus the average of 22 per cent among all claimants.

Claimants receiving ESA for up to a year were more likely to be volunteering than claimants receiving UC for up to a year (9 per cent versus 4 per cent).

The relationship between work and volunteering is discussed further below.

4.2.2 The relationship between volunteering and paid work

Voluntary work can be a precursor to paid work in the near future but this is not always the case. Those in voluntary work currently were polarised between those

who felt they could undertake paid work in the near future, and those who did not think they could ever undertake paid work. Those who did not think they could ever undertake paid work outweighed those who felt undertaking paid work in the near future was a possibility.

On the one hand, some claimants who were currently volunteering were more likely than the average among all claimants to feel that they could enter paid work within the next two years (28 per cent of those currently volunteering versus ten per cent overall).

The qualitative findings may suggest some of the reasons for this. Many claimants in the in-depth interviews and focus groups saw voluntary work as a 'safe space' where they could gain experience and skills but without the commitment required for paid work or the risk of losing their benefits.

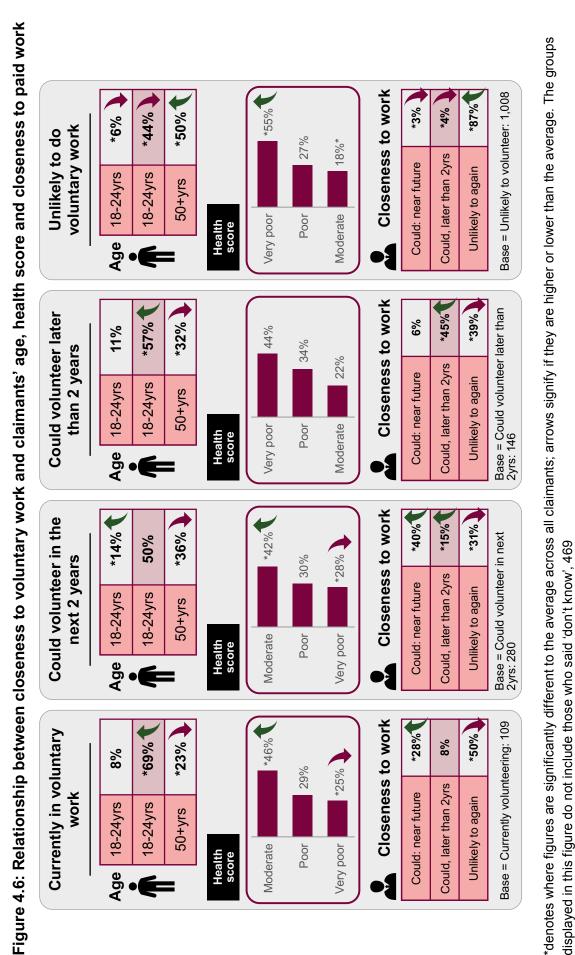
'I used to do some voluntary work ... They are good at understanding when you don't have good days. It's not always possible to be ... a functioning adult getting along with no problems ... if you ring up and somebody says "do you know what, don't worry about it today, thank you for ringing, just try and get yourself in tomorrow", that's so much better than saying "right, now you're fired, you're losing your house, you're losing your money".'

(Female, 25+, focus groups)

On the other hand, the survey findings also showed that a much higher proportion of those currently in voluntary work (47 per cent) felt that their health meant they would never be able to undertake paid work in the future.

Again, this is reflected in the qualitative findings. While some of the claimants in the in-depth interviews and focus groups saw voluntary work as a stepping stone towards paid work; not all did. Volunteering was seen by some as being preferable to paid work, because undertaking paid employment meant risking losing their benefits. These barriers to work were also found among those who were not volunteering and are discussed further in Section 4.3 below.

The notable overall trends in these relationships are illustrated in Figure 4.6.



4.3 Barriers to employment

This section describes the factors that claimants feel prevent them from being able to work. In the survey, all claimants except a minority who were terminally ill or already working, were given a list of 15 statements about perceived barriers to work and asked to what extent they agreed or disagreed with them on a scale from 1 (strongly disagree) to 5 (strongly agree). The statements were developed using findings from the in-depth interviews and focus groups. Figure 4.7 shows the list of statements that claimants were asked about and the percentage that agreed with each of them (i.e. those giving either a score of 4 or 5 in response to each statement). It thus shows the prevalence of each barrier among claimants.

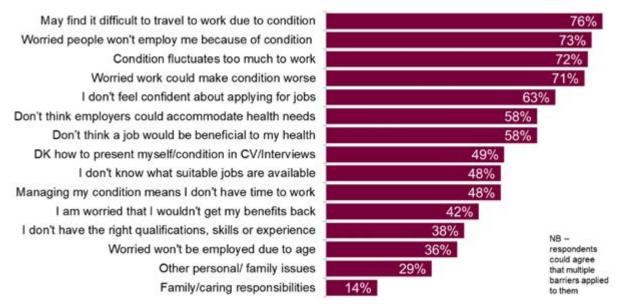
It is notable that claimants were facing multiple barriers that prevented them from working. Nearly all claimants (98 per cent) who answered the question agreed with more than one barrier. On average, claimants agreed with 7.5 barriers out of the 15 presented.

Health-related barriers were more likely to affect claimants than employment-related ones. Claimants were more likely to be concerned that their health would impinge on their ability to gain or maintain employment, or that working would have a negative impact on their health, and less likely to say that they had a lack of qualifications or skills to gain paid work or that other personal issues or caring responsibilities prevented them from working. At least seven in ten claimants agreed that:

- I may find it difficult to travel to work with my health condition (76 per cent).
- I am worried people won't employ me because of my health condition (73 per cent).
- My health condition/disability fluctuates too much for me to work (72 per cent).
- I am worried that working could make my health condition worse (71 per cent).

The survey findings about barriers are explored in more depth in section 4.3.2 below.

Figure 4.7: Agreement with statements about barriers to employment³⁷



Base: All, excluding terminally ill, those in paid work, and those who said that the barrier in question was irrelevant to them because of the severity of their health condition. Base sizes vary between 1,189 and 1,330 according to the number of respondents who said the barrier in question was irrelevant to them because their health condition rules out work.

4.3.1 Qualitative findings on barriers to employment

While the survey findings show the prevalence of the perceived barriers, the qualitative findings give an indication of which barriers were perceived to be most powerful, and of how some of these barriers interact. For instance, although concerns about having difficulty travelling to work was the most prevalent barrier found in the survey, it did not feature as a powerful barrier qualitatively: claimants in the focus groups noted that public transport was costly and challenging, but this was raised as a secondary issue rather than as one of their key barriers to work.

Health-related barriers

Health-related barriers were widely cited as a powerful barrier in the in-depth interviews and focus groups. For some, pain management was a considerable barrier to work, particularly among those with musculoskeletal problems or other conditions resulting in chronic pain. Improved pain management regimes would be a necessary precursor to these individuals undertaking work, and some noted this would require their regime improving to ensure that any treatment did not cause drowsiness. For some other individuals, their shortness of breath (especially those with heart conditions), fatigue and dizziness were also seen as key barriers to working that would be difficult to overcome.

For many others, better support for a mental health condition was needed. It was common for claimants to raise the issue of long waiting lists and a lack of sustained provision (e.g. a maximum of six funded sessions before the support came to an

³⁷ The full question and statement wordings can be found at questions F1 to F4 on Annex D: Survey Questionnaire

end) and inconsistent support from a number of different professionals. More help around managing anxiety linked to starting work and meeting new people was also frequently mentioned. Related to this, many claimants, particularly younger individuals with a mental health condition, also felt that they needed to build self-confidence and routines, in the first instance by engaging more with everyday life, before being work-ready.

Skills-related barriers

In the focus groups, some individuals wanted help with how to present themselves, including their condition/disability in their CV as they struggled to explain health-related gaps in their work history in a professional way. Similarly, some expressed an interest in support to help get and prepare for job interviews to ensure they presented themselves in the best possible way.

Access to training courses was also cited by some, particularly among older individuals who had previous work experience but felt they could not return to the same role and needed to re-train.

Employer attitudes

Barriers relating to employer attitudes were mentioned by many in the focus groups and in-depth interviews. For some, the main barrier to employment was a perceived lack of understanding, awareness and flexibility among employers in relation to hiring people with a health condition or disability. These discussions focused on employers in both the private and public sector. Some claimants gave examples of instances where they had positive relationships with their line managers who were supportive, recognised their needs and meant the workplace could be flexible around their health condition or disability.

However, they often also had examples of more negative experiences of a different manager, which contributed to them leaving a role, because they were not disability-aware. It was common for claimants with previous work experience to recount instances where they had felt talked down to, bullied or discriminated against in the workplace. Some were worried about being considered a 'trouble maker' if they encountered a problem and had to ask for support or adjustments to be made.

Furthermore, a few felt that some employers may try to avoid taking on people with a long-term health condition or disability in order to avoid having to change their ways of working or pay for adaptations to be made. Some individuals with hearing impairments felt that they had missed out on paid roles they applied for because prospective employers were not willing to pay for an interpreter to enable them to participate in regular meetings.

'The manager was very supportive, recognised my needs, recognised any problems, gave me help when he needed it ... and invited me to meetings. When they left, the new person didn't involve me in meetings, they just weren't bothering to include me ...I would ask for an interpreter but they would say I can have their notes and that we don't need to bother with that service.'

(Female, 25+, focus groups)

Perceived pay gap

Some felt that starting paid employment might jeopardise their financial position. This was related to a perceived 'pay gap': the period between benefit payments ceasing and the first pay cheque from a new job being received, as well as to the possibility that employment might not work out, resulting in individuals subsequently struggling to re-apply for benefits (or struggling financially while their application was being processed).³⁸ Peer-to-peer interview participants were also concerned about the financial implications of coming off benefits; for example, one individual mentioned that although they were keen to work, they felt they would not be able to do enough work to cover their living costs.

Risk of 'failing' and perceived high stakes of entering work

The in-depth interviews and focus groups also identified a wider, more nuanced set of inter-linked barriers, relating to the risk of 'failing' and the perceived high-stakes of entering work.

Uncertainty about their health and how they would handle moving into paid work was a considerable concern for some claimants. They were worried about starting a job and then finding that they were unable to cope with it due to their health condition. Those with fluctuating conditions were also concerned that they might be able to perform in their new role during a 'good period' but struggle to do so when their symptoms worsened. For example, several claimants with mental health conditions had good and bad days or weeks, and others with physical conditions such as fibromyalgia, or mobility problems with the legs and back experienced more severe symptoms in the winter months. They referenced several perceived risks following on from this.

Firstly, they worried about the immediate financial impact of being without an income between leaving a job and receiving benefits, and the risk of not being able to afford their rent or mortgage during this time (particularly if housing benefits had been withdrawn as a result of ending their ESA claim i.e. the perceived pay gap discussed above). This concern was more common in the focus groups among those with an interest in returning to work.

Secondly, they were concerned about having to reapply for benefits, when this had been difficult in the first place. The specific concerns about this varied and included: finding forms (and 'life admin' generally) difficult, stressful or overwhelming, and being worried about not being able to access the support needed to successfully fill these in; previous experiences of finding the Work Capability Assessment stressful and/ or demeaning; and worrying that they will be found 'fit to work' if they apply again, because the attempt to enter work might be taken as proof that work were possible. Again, this concern was more common in the focus groups.

³⁸ Individuals who have a 26-week continuous claim for Income related ESA (ESA(IR)) prior to starting work can receive Housing Benefit Run On for four weeks. Housing Benefit Run On was introduced to help bridge the gap between the end of a benefit claim and starting work. As an in and out of work benefit Universal Credit is more flexible: when claimants move into work their UC claim remains open and adjusts automatically to take account of their earnings; if their employment ends their UC award will increase to recognise the drop in income, without the need to make a new claim.

Thirdly, there was a more personal fear of failing – in terms of letting themselves or their employers down.

'I am scared to work ... scared of being embarrassed and being behind.'

(Male, 25-34, in-depth interviews)

These concerns were compounded by the fact that some individuals were already struggling financially to cover their housing costs and had previous experience of getting into rent arrears because of issues with their benefits. There were some instances where individuals had previously been homeless and so it was easy for them to imagine a situation where this could happen again.

By comparison, individuals' current position in the ESA Support Group was often perceived as a stable place, in which they could concentrate on improving or stabilising their health, with less of the financial pressures that might compel them to find paid work (and thus potentially jeopardise their health). Concern that even showing an interest in moving towards work would trigger a reassessment and cause their current benefit claim to end, was common in the focus groups, when discussing the possibility of returning to work. This concern about work-related activity jeopardising the stability of being in the ESA Support Group (which claimants felt was a struggle to prove they qualified for) was a powerful barrier to work expressed in the qualitative phase, due to the perceived serious consequences of losing benefits and having to reapply.

4.3.2 Quantitative findings on variations in barriers to employment by demographics

In this section we return to the barriers that claimants reported in the survey and examine how they differ by various claimant characteristics.

Variations in barriers to employment by age

The survey showed that the number of perceived barriers tended to increase with age (18 to 24 year olds agreed with an average of 6.8 barriers while both 25 to 49, and over 50 year olds agreed with an average of 7.5 barriers). Older claimants were more likely to worry about health or age-related barriers. For example, more than half of over 50-year olds felt that people would not employ them because of their age (55 per cent); and three quarters (75 per cent) were worried that paid work could make their health condition worse. Older claimants were, however, less concerned about lacking skills and knowledge (32 per cent versus 38 per cent on average among all claimants) or having other issues to address (23 per cent agreed that they have other issues that need to be sorted before they can consider working, versus 29 per cent of claimants overall).

Younger claimants, between 18 and 24 years old, were more likely to say that they don't have the right qualifications or experience (54 per cent versus the average of 38 per cent) and that they don't know how to present themselves in CVs and interviews (62 per cent versus 49 per cent on average).

Variations in barriers to employment by condition

As might be expected, the number of barriers experienced increased with severity of health condition: the average number of barriers experienced was 6.8 among claimants with a moderate health score, but 7.7 among those with a very poor health score, and 7.8 among those with a poor health score. Similarly, claimants who felt their condition rules out work reported an average of 8.3 barriers.

The average number of barriers experienced was also higher among those who said their health condition would get worse (average of 8 barriers), those that felt it would last the rest of their lives (average of 7.7 barriers) and those whose conditions fluctuated (average of 7.6 barriers, compared with 7.2 for those whose conditions do not fluctuate).

People with mental health conditions were considerably more likely to perceive a higher number of barriers to working than average. As shown in Table 4.2, 33 per cent of those with a mental health condition as their main condition and 31 per cent of those with any mental health condition agreed with over ten barriers, compared with 20 per cent of those without a mental health condition.

Number of reported barriers	All claimants with a mental health condition	Claimants whose main condition was mental health	Claimants without a mental health condition	Average among all claimants with any condition
0	1%	2%	3%	2%
1-3	8%	10%	11%	9%
4-9	*61%	*56%	*67%	63%
10-15	*31%	*33%	*20%	26%
Mean number of barriers agreed with:	*7.8	*7.8	*6.9	7.5

Table 4.2: Number of barriers perceived by claimants with mental
health conditions

Base: First column: Mental health any (653), Second column: Mental health condition as main condition (216), Third column: Claimants who did not have a mental health condition (425), Fourth column: All except those in paid work, those with a terminal illness and those who said that the barrier in question was irrelevant to them because of the severity of their health condition (1,088) *denotes significant differences from the average for all respondents.

Despite reporting more barriers, claimants with mental health conditions were slightly more likely to say that paid work would be beneficial to their health, although the proportion who felt this is still relatively low (25 per cent of those with a mental health condition as their main condition and 20 per cent of those with any mental health condition, versus 18 per cent of all claimants who answered the question).

Variations in barriers to employment by benefits and employment history

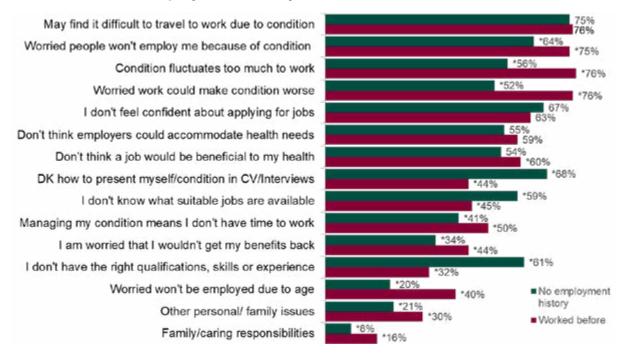
Most barriers were more prevalent among claimants who had worked before, than among those with no employment history. As Figure 4.8 shows, there were only three barriers that were significantly more prevalent among those who had never been in paid work, and all were related to employment skills and qualifications rather than health. Claimants who had never worked before were more likely:

- To say they did not know how to present themselves and their health condition or disability in CVs or interviews (68 per cent of those who had not worked before, versus 44 per cent of those who had).
- To feel they did not have the right qualifications, skills or experience than those who had worked before (61 per cent versus 32 per cent).

And to feel they did not know what suitable jobs are available than those who had worked before (59 per cent versus 45 per cent).

These differences can be explained by examining the characteristics of those who had never worked before. Claimants who had never worked before were considerably more likely to have no qualifications than the average among all claimants (58 per cent compared to 34 per cent) and to struggle to use the internet (56 per cent compared to 42 per cent). They were also more likely to feel their health condition rules out work (70 per cent compared to 59 per cent). They were less likely to have a condition that fluctuated (54 per cent had a condition that fluctuated compared to 66 per cent overall) and expected it to stay the same (39 per cent compared to 24 per cent), although differences by health score were not conclusive.

Figure 4.8: Agreement with statements about barriers to employment, worked before versus no employment history³⁹



Base: All, excluding terminally ill and those who said that the barrier in question was irrelevant to them because of the severity of their health condition. Base sizes vary between 1,189 and 1,330 according to the number of respondents who said the barrier in question was irrelevant to them because their health condition rules out work.

Overall those who have worked before were significantly more likely to report health-related barriers. However, those who had recently been employed were more likely to feel that having a job would be beneficial to their health and that an employer could accommodate their health needs. Thirty-two per cent of those who had worked within the last year felt a job would be beneficial to their health versus 18 per cent overall, and 23 per cent of those who had worked in the last five years thought that an employer could accommodate their health needs versus 18 per cent overall.

Variations in barriers to employment by other subgroups

The number of barriers reported also varied according to living arrangements. The average number of barriers increased from 7.5 among all to 7.8 among those living in a couple, and to 7.9 among those who had dependent children.

Claimants who were unable or struggled to use the internet were more likely to say that they did not have the right qualifications, skills or experience (51 per cent agreed versus 38 per cent of all claimants) and did not feel confident about applying for jobs (68 per cent agreed versus 63 per cent of all claimants).

³⁹ The full question and statement wordings can be found at questions F1 to F4 on Annex D: Survey Questionnaire

4.3.3 Relationship between reported barriers to employment and closeness to paid work

We looked specifically at how agreement with the 15 statements about barriers varied between those who felt they were closer to, and further away from being able to undertake paid work in the future, according to the 'closeness to work' variable (as described in section 4.1).

The proportions who agreed with each barrier statement are presented in Table 4.3. The five most common barriers for each group are coloured red, the five least common are green and the middle five are coloured yellow, to demonstrate how the prevalence and ranking of the barriers differed for those who thought they could undertake paid work in the near future (within two years), in the further future (later than two years) and those who thought their health condition rules out work.

Barriers to employment	All	Could work in the near future	Could work later than 2 years	Health rules out work
	% agree	% agree	% agree	% agree
May find it difficult to travel to work due to condition	76%	*56%	81%	*82%
Worried people won't employ me because of condition	73%	71%	*83%	74%
Condition fluctuates too much to work	72%	*53%	71%	*80%
Worried work could make condition worse	71%	*56%	66%	*80%
I don't feel confident about applying for jobs	63%	*52%	61%	*68%
Don't think employers could accommodate health needs**	58%	*32%	*46%	*73%
Don't think a job would be beneficial to my health**	58%	*27%	*44%	*77%
DK how to present myself/condition in CV/Interviews**	49%	*41%	47%	*52%
I don't know what suitable jobs are available	48%	*41%	45%	*52%
Managing my condition means I don't have time to work	48%	*28%	44%	*61%
I am worried that I wouldn't get my benefits back	42%	*53%	48%	*38%
I don't have the right qualifications, skills or experience	38%	37%	40%	*44%
Worried won't be employed due to age	36%	*28%	37%	*40%
Other personal/ family issues	29%	*40%	33%	*26%
Family/caring responsibilities	14%	11%	*24%	14%
MEAN:		*6.3	*7.7	*8.3

Table 4.3: Barriers experienced by closeness to work

** previously phrased in the positive

Base: All, excluding terminally ill and those in paid work. Base sizes for 'health rules out work' vary between 529 and 670 according to the number of respondents who said the barrier in question was irrelevant to them because of the severity of their health condition. Other bases: Could work in near future (219), Could work later than 2 years (170.)

As shown in the table, the average number of reported barriers increased with the perceived distance from paid work, with those who felt they could work in the near future experiencing an average of 6.3 barriers, those who felt they could work in the further future having an average of 7.7 barriers and those who thought their health rules out work having an average of 8.3 barriers.

The most prevalent/highest ranked concerns across all three groups were broadly similar, although there were some notable differences:

- "I don't think work would be beneficial to my health" featured in the top 5 barriers for the 'health rules out work' group, but the bottom 5 for those who felt they could move into paid work (either in the near future or later than 2 years).
- Those considering paid work to be a possibility in the near future were more likely to fear not being able to return to benefits (53 per cent agreed versus 48 per cent of those who felt they could work in the further future and 38 per cent of those who thought their health condition rules out work).
- Those who saw themselves working in the near future were also more likely to be concerned about personal or family issues preventing them from working (40 per cent agreement versus 33 per cent among those who felt they could work in the further future, and 25 per cent among those who thought their health rules out work).
- A lack of confidence in applying for jobs seemed to be a differentiating factor for those considering paid work in the further future (61 per cent agreed versus 52 per cent of the 'near future' group and 38 per cent of those who thought their health rules out work).

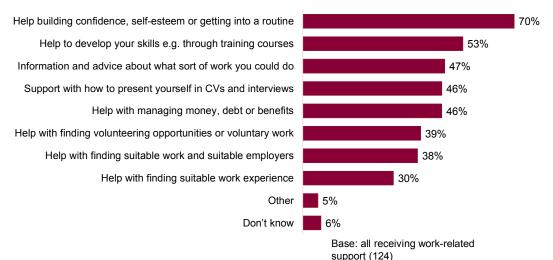
5 Views on employment-related support

This chapter considers to what extent claimants were currently receiving employment-related support, and who they were receiving support from. It then looks at how interested claimants were in various forms of support in future.

5.1 Existing employment-related support

As might be expected given that only 22 per cent of claimants were either working (two per cent) or felt they might be able to work in future (20 per cent), only eight per cent of claimants were receiving work-related support (whether from JCP or elsewhere) at the time of the survey. Among these 124 claimants, help with building confidence, self-esteem or getting into a routine was the most commonly received form of support (by 70 per cent of those currently receiving support), while help finding voluntary work (39 per cent), suitable employment/employers (38 per cent) or work experience (30 per cent) were the least commonly received forms of support (Figure 5.1).

Figure 5.1: Employment-related support currently being received



"Which of the following forms of support are you currently receiving to help you?"

Who work-related support was received from

Existing work-related support was most commonly received from a carer, relative or friend (44 per cent). This was more than twice as common than support received from other sources, including more 'professionalised' ones. The next most-mentioned were: a support worker (21 per cent), a family doctor/GP (18 per cent), a mental health

worker (17 per cent); a counsellor or therapist (17 per cent); a charity worker from an organisation linked to the individual's health condition/disability (16 per cent); and an individual at a college or other education institution (12 per cent).

Only eight per cent of those receiving work-related support – a total of 13 claimants were currently receiving it from a Jobcentre Plus (JCP) Adviser or work coach⁴⁰.

5.1.1 Subgroup analysis

With the caveat that this analysis is based on only 124 claimants and so should be treated with caution, the following subgroup differences were identified among those receiving work-related support:

- **Age:** Younger claimants were more likely to be receiving work-related support (20 per cent of 18-24 year olds, versus eight per cent of all).
- **Health condition:** Those with a better outlook in terms of health were more likely to be receiving work-related support. For example, 14 per cent of those with a moderate health score were receiving work-related support, as were 21 per cent of those who expect their condition to improve and 26 per cent of those who thought they could work in the near future.
- Benefits and employment history: Those receiving work-related support were more likely to have been on out of work benefits for under a year (20 per cent of those on benefits for under a year, versus eight per cent overall). Conversely, the likelihood of receiving help decreased as time on benefits increased (5 per cent of those on out of work benefits for over 10 years were receiving work-related support, versus 8 per cent overall).
- **Volunteering:** Approaching a third (30 per cent) of those who said they were currently volunteering were receiving work-related help and support. This support may have been delivered or received through the voluntary work, or, alternatively, the support may have been a factor in helping them volunteer.
- **Ethnicity:** Black and Minority Ethnic (BAME) claimants were also more likely than white claimants to be receiving work-related support (14 per cent of BAME claimants, versus 8 per cent of white claimants).
- Universal Credit (UC) and Employment and Support Allowance (ESA): There were no significant differences between UC and ESA claimants, once time on benefits had been taken account of.

⁴⁰ There is no requirement for those in the ESA Support Group or UC equivalent to visit JCP, therefore those claimants who do attend are voluntarily engaging with JCP.

5.2 Interest in future employment-related support

In the survey, all claimants (excluding those who were terminally ill) were asked how interested they were in receiving various forms of support.⁴¹ The proposed forms of support were a mixture of categories used in other Department for Work and Pensions surveys, and categories developed from the qualitative findings.

Around a third (32 per cent) of claimants were interested in at least one form of support and around two-thirds (68 per cent) were not interested in any of the forms of support.⁴² Those not interested in any of the forms of support were more likely to have never worked before; to say they were unlikely to work again; to have a low health score and poor prognosis; to be older; to have been on out of work benefits for over 10 years; to have no qualifications; and to have low digital skills and limited access to the internet.

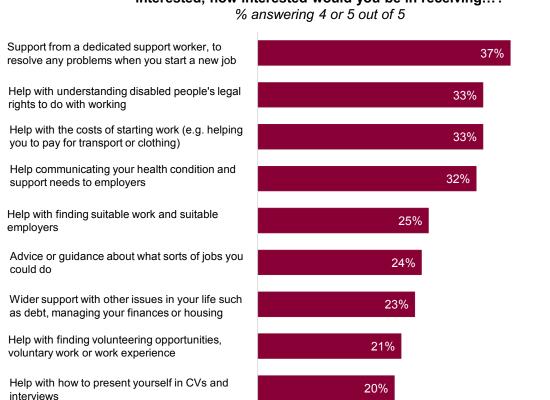
The proportion of claimants interested in each individual type of support is shown in Figure 5.2.⁴³ There was most interest in the following forms of support: a dedicated support worker to "troubleshoot" for them when they obtained a new job role (37 per cent); help with understanding disabled people's rights (33 per cent); help with the costs of starting work (33 per cent); and help communicating one's health condition and support needs to employers (32 per cent). The relatively high level of interest in help with the costs of starting work reflects the 'pay gap' concern, i.e. the period between the points at which benefits end and the first pay check is received, which was also found in the focus groups.

⁴¹ Claimants who felt their health condition rules out work, also had the option of saying that the forms of support were irrelevant to them because of the severity of their health condition. These individuals who dismissed the support altogether because of the severity of their health condition have retrospectively been removed from the base.

⁴² The former figure represents the percentage of all 2,012 respondents who said they were 'interested' or 'very interested' in at least one of the forms of support, and the latter figure represents the percentage of all 2,012 respondents who did not say they were 'interested' or 'very interested ' at least one of the forms of support.

⁴³ Note that, as the bases of these questions do not include those who said the support option in question was irrelevant to them because of the severity of their health condition, the base sizes vary between 1,166 and 1,236 according to the number of respondents who said the support in question was irrelevant to them.

Figure 5.2: Interest in employment-related support



On a scale of 1 to 5, where 1 means not at all interested, and 5 means very interested, how interested would you be in receiving...?

Base: All, excluding terminally ill and those who said that the form of support in question was irrelevant to them due to the severity of their health condition. Base sizes vary between 1,166 and 1,236 according to the number of respondents who said the form of support in question was irrelevant to due to the severity of their health condition.

5.2.1 Relationship between interest in employment-related support and closeness to paid work

Table 5.1 shows how claimants' interest in further employment-related support varies according to their distance from paid work. Within each column, the cells shaded green indicate higher levels of interest; those shaded orange indicate moderate levels of interest; and those shaded red indicate lower levels of interest, in order to make patterns more evident.

Claimants who thought they would be able to work in the future were significantly more interested in all forms of support, and relatively more interested in immediate, practical forms of support such as advice about what jobs they could do and help with finding suitable employers.

Those who were interested in paid work, but thought this would be further in the future (i.e. in more than two years' time), were differentiated by more frequently reporting the need for help with communicating their health condition and support needs to employers.

	All	Could work in near future	Could work later than 2 years	Health rules out work
	% interested	% interested	% interested	% interested
Support from a dedicated support worker, to resolve any problems when you start a new job	37%	54%	51%	26%
Help with the costs of starting work (e.g. helping you pay for transport or clothing)	33%	57%	50%	20%
Help with understanding disabled people's legal rights to do with working	33%	47%	48%	24%
Help communicating your health condition and support needs to employers	32%	48%	55%	20%
Help with finding suitable work and suitable employers	25%	49%	36%	11%
Advice or guidance about what sorts of jobs you could do	24%	47%	37%	12%
Wider suppport with other issues in you rlife such as debt, managing your finances or housing	23%	40%	30%	16%
Help with finding volunteering opportunities, voluntary work or work experience	21%	31%	35%	15%
Help with how to present yourself in CVs and interviews	20%	37%	35%	10%
MEAN:		4.1	3.8	*0.6

Table 5.1: Interest in further support, by distance from paid work

Base: All, excluding terminally ill and those who said that the form of support in question was irrelevant to them due to the severity of their health condition. Base sizes for 'health rules out work' vary between 464 and 534 according to the number of respondents who said the form of support in question was irrelevant to them due to the severity of their health condition. Other bases = Could work in near future (219), Could work later than 2 years (170).

While those who felt they could undertake paid work in the near future (within two years) were more interested in most forms of support than those who felt they could work later than this, both of these groups were significantly more interested in support than those who said their health rules out work. This indicates that individuals saying they 'could work' is a stronger indicator of openness to support than the timeframe they give for this. Similarly, there were no significant differences between the numbers of forms of support claimants were interested in, for those who thought they 'could work in the near future' versus those who thought they 'could work in more than two years' time' – however there were significant differences between both of these groups and those who said their health rules out work. For example, 37 per cent of those who thought they could work again in the near future and 33 per cent of those who thought they could work again in more than two years' time were interested in over five forms of support, compared with only 4 per cent of those who said their health rules out work.

While the qualitative research found that those who were involved in volunteering tended to perceive themselves as being fairly likely to work in the future, and some saw their volunteering as a stepping stone to paid employment, it is notable that the quantitative research found that those who thought they might be able to work in the future were relatively uninterested in volunteering (i.e. compared with other forms

of support) – indicating that in many cases, if individuals feel capable of working, whether now or later, they will be interested in work that is paid.⁴⁴

5.2.2 Other subgroup analysis on employment related support

Demographics

Younger people were more likely to be interested in multiple forms of support: nearly a fifth of 18-24 year olds (19 per cent) were interested in over five of the listed forms of support. This interest dropped off among older claimants, with only 8 per cent of those aged 50+ interested in over five forms of support. This is likely to be related to a diminished interest in entering work more generally: for instance, 52 per cent of claimants who felt their health ruled out work were over 50 years old, while only 28 per cent of claimants who felt that future paid work was possible were over 50 years old – see section 4.1.4.

Health condition

Individuals with mental health conditions (either any mental health condition, or a mental health condition as their main condition) were significantly more likely to be interested in all of the listed forms of support, perhaps related to the qualitative finding that those with mental health conditions were often frustrated by the difficulty of accessing sustained support (see section 3.1.3).

More specifically, individuals with mental health conditions were more likely to be interested in wider support with issues in their life such as debt, managing finances, and housing (nearly a third of those with a mental health condition as their main condition and 27 per cent of those with any mental health condition, versus 23 per cent overall).

Considering all health conditions, those with a more positive situation in terms of their health also appeared to be more interested in support: 65 per cent of those who expected their condition to improve were interested in at least one form of support (compared with 32 per cent for all claimants), and 40 per cent of those with a moderate health score were interested in at least one form of support (again, compared with 32 per cent for all claimants).

Benefits and employment history

Those claimants who had been on benefits for under a year were less interested in most forms of support. This may be because they were more likely to be already receiving support (see section 5.1.1). The focus groups also suggested that such claimants might be less interested in support because they had only just gone onto benefits and were adjusting to their new situation and trying to achieve some stability in their situation before looking at support options.

Claimants who had been on out of work benefits for between one and three years were most likely to express interest in multiple forms of support, indicating that

⁴⁴ The qualitative research also found that individuals aiming to work in the near future were mainly interested in part- or full-time work, rather than volunteering.

this may be a 'window of opportunity', i.e. after their health condition/disability has stabilised, but before being out of work becomes entrenched.

Other subgroups

- **Digital skills:** Confident and expert users of the internet were more likely to be interested in employment related support (52 per cent of these individuals were interested in at least one form of support, versus 32 per cent of all claimants).
- Work history: Interest in help with understanding disabled people's legal rights was higher among those who had undertaken paid work before (35 per cent of those who had worked before were interested, versus 25 per cent of those who had not worked before), indicating that those who had worked before were more likely to recognise the relevance and applicability of such advice.
- Ethnicity: BAME claimants were more interested than white claimants in nearly all the listed forms of support (for example, 39 per cent of BAME claimants were interested in help with finding suitable work and employers, versus 23 per cent of white claimants), and were more likely to be interested in multiple forms of support (for example, 19 per cent of BAME claimants were interested in over 5 forms of support, as compared with 10 per cent of white claimants).
- Universal Credit (UC) and Employment and Support Allowance (ESA): ESA claimants who had been on benefits for one to two years were more likely than UC claimants who had been on benefits for the same period of time to have no interest in any of the forms of support (68 per cent of ESA claimants, versus 52 per cent of UC claimants). Aside from this, there were no significant differences between UC and ESA claimants, once time on benefits had been taken into account.

5.2.3 Qualitative findings on interest in forms of employment related support

The qualitative findings illuminate the reasons for claimants' interest in some of the most popular of these forms of support.

A dedicated support worker to "troubleshoot" for them in a new job role

Some claimants in the focus groups talked about wanting a dedicated support worker to "troubleshoot" for them in a new job role, to speak up for them in the case of disputes, to addresses issues such as bullying or discrimination, to help them ask for adjustments, and to explain how their disability might be affecting their ability to do particular tasks.⁴⁵ A few saw this advocate as an informal 'buddy', while others conceived this as a more formal advocate.

'It would be easier to go back to work [with in-work support] because you don't feel looked down on and it's embarrassing as well. I don't think people understand how shameful you feel after having a breakdown.'

(Female, 25+, focus groups)

⁴⁵ Focus group participants were also presented with the 'support worker concept', discussed in Section 5.3 below; however some individuals spontaneously mentioned the idea of a dedicated support worker before it had been introduced.

'I [envision it] ... almost like a mentoring system. So ... there's somebody within the organisation whose job it is to look after people in those situations who might need that extra help. So for them to walk around the building with that person and say is this accessible? If it's not, it's [up to] them to liaise with building management to try and make it more user-friendly...'

(Female, 25+, focus groups)

Claimants with hearing impairments said that the existence of individuals (such as supportive line managers or colleagues) who informally played an advocate-type role for them could make or break experiences of employment. For example, individuals who had had line managers in the past who had made sure interpreters were employed as often as possible and immediately addressed issues of bullying, said that they had tended to stay on in these jobs even if the job itself wasn't particularly suitable. On the other hand, if a good line manager left and was replaced by somebody who didn't understand how to engage with them, this might result in them leaving a job that they otherwise liked.

Help with understanding disabled people's rights in the work place

Interest in knowing disabled people's rights in relation to employment arose in the focus groups, in the context of many participants having experienced very poor treatment by employers in the past. Some of the younger individuals in the focus groups recounted their experiences with employers; and the older, more legally-aware individuals then pointed out to the younger ones that their rights had been violated, and they should have received support in defending them. For example, one individual was fired for attending GP appointments, as this was recorded as an unauthorised absence. Some participants felt that they would have more confidence to speak up for their rights if they were able to quote legislation supporting them, and would have welcomed training on these issues.

Older claimants in particular tended to feel that changes in societal and employer attitudes were needed as a precursor to being able to work. They felt that even constructive forms of Occupational Health support are currently too focused on specific adaptations and not enough about the holistic experience of working (encompassing employer and colleague attitudes).

Help with finding suitable work and suitable employers

Many participants in the focus groups saw help with identifying appropriate roles and employers as vital. They recognised that whether a particular job would turn out to be beneficial or harmful for them depended on how understanding of their disability their employer and/or line manager were. Some individuals couldn't entertain the idea of working until they had received reassurance that they would be able to find an employer able to meet their needs. This was a particular concern for individuals with hearing impairments and other sensory impairments.

"The thing that puts me off, education or work, is having to fight non-stop ... to get people to understand."

(Female, 25-34, in-depth interviews)

Similarly, one individual in the peer-to-peer interviews, who had a visual impairment, was very keen to work and would have welcomed help with finding suitable

employers, as they were doubtful that any employer would be able to accommodate their needs.

Help with the costs of starting work

Some participants in the focus groups noted that support with the costs of starting work, for example, transport, childcare, and clothing, would be helpful in getting them into work.

Some pointed out that they wouldn't have been able to attend the focus groups without the provision of a taxi service, as public transport was too costly and challenging, and the same thing applied to attending job interviews and working itself. Some individuals in both focus groups and in-depth interviews pointed out how reliant they were on friends and relatives to help get them around, which would not be sustainable if working full-time (discussed further in Chapter 4).

A few focus group participants highlighted the problem posed by what one termed the 'pay gap'; the period between when your benefits end due to you starting a new job, and the point at which you receive your first pay cheque. Due to work-related and daily living expenses that are accumulated in this period, the 'pay gap' had in the past led to sustained financial difficulties for a few individuals, with one individual having been forced to take out a pay-day loan to prop up their finances during this period, and subsequently having developed problem debt. This individual identified the 'pay gap' as the key barrier to him re-starting employment, and said that the most fruitful forms of support for him would be directed towards overcoming the pay gap issue, for example, allowing employment benefits to continue throughout the pay gap period or making available low-interest loans that could easily be repaid once individuals had been in a job for a few months.

'Getting back into work costs a lot of money. You need all the fresh clothes, you need shoes, you need your fare to get there, even eating at work ... you need to have a budget plan.'

(Male, 25+, focus groups)

As a related point, some focus group participants also noted that help with access to transport and childcare was also necessary to enable them to take up employment-related support. Some individuals also suggested that a support worker could help individuals out with budgeting to manage the costs of working. A few participants with young children mentioned crèches and childcare support (or a lack thereof) as a reason why certain forms of work-related training or treatment options were, or were not, appealing.

It is worth noting that help with the costs of starting work is already available from DWP via Access to Work: a publicly funded employment support programme that aims to help more disabled people start or stay in work, by providing practical and financial support with help or adaptations that go beyond the reasonable adjustments that employers are required to make under the Equalities Act 2010. However, the qualitative research found that awareness of Access to Work among claimants is low (see section 5.4).⁴⁶

⁴⁶ The Flexible Support Fund also offers tailored back-to-work support where Jobcentre Plus advisers have flexibility and discretion to make awards that will enhance the employment prospects of claimants. It can be used to provide additional funding to help remove barriers to work, such as the cost of clothing, travel and childcare.

5.3 Views on the concept of a support worker, to deliver future employment-related support

In the depth interviews claimants had found it difficult to picture the types of support they would find helpful. To help stimulate thoughts and discussion, focus group participants were presented with a description of a support worker concept, developed around some of the issues that arose in the depth interviews.⁴⁷

This was described as: 'A dedicated case-worker who would provide 1-2-1 intensive support tailored to your individual needs. They would work with you to identify your support needs based on your circumstances, help to prioritise these and support you to access appropriate help.'

When presented with this model, there was broad support for the idea. Even among those individuals who found it difficult to think constructively about support needs due to negative experiences with employment, healthcare, and the benefits system in the past, there was widespread acknowledgement that the support worker model was something that would be useful.

Ideas about what this individual would do varied, but often involved them working with the individual prior to them starting work, helping them with the transition into work, and providing them with in-work support – particularly to help the individual acclimatise themselves to their new workplace, and act as an advocate to help get any problems resolved (leaving the individual to focus on their job).

Individuals also wanted the support worker to help them liaise with the Department for Work and Pensions (DWP) or Jobcentre Plus (JCP) if the role didn't work out, to avoid them having to reapply for benefits 'from scratch'.

'I don't want to have to do a new application form [if the job doesn't work out] to go back on [a disability benefit] that I was already on before.'

(Female, 25+, focus groups)

Some individuals were uncomfortable about the idea of the support workers being employed by DWP or JCP, and wanted the role to be provided by trusted parties such as charities. Others, however, did not express any reservations about the idea of support workers being provided by DWP or JCP.

5.3.1 Key features of effective support

For the support worker to be effective, it was important to individuals that the support worker be able to work with them intensively for a sustained period, to allow trust to develop.

'You've got to build up the trust with people and that's why you need longer sessions. You can't just be bonding with people when they're leaving and then doing the same thing over and over again.'

(Female, 25+, focus groups)

⁴⁷ The focus groups were conducted with claimants in the ESA Support Group with at least some interest in paid work.

Discussion of this also highlighted other characteristics that individuals wanted from people providing support, including:

- **Good interpersonal skills**, such as being compassionate and listening, and being able to treat individuals like a friend rather than like an authority figure who applied pressure to make individuals do things they weren't ready for. Some participants wanted the option to change support workers if a particular support worker wasn't a good fit, in interpersonal terms.
- Continuity, with individuals saying that a support worker would have to be reliable, as they had had negative experiences of being bounced around between different support services in the past. They noted that engaging in a trusting relationship with somebody is high risk, and with a potentially very high emotional cost should the investment in the relationship not pay off. Some individuals were thus concerned about receiving support for only a limited period, before it being withdrawn due to cuts, and were reluctant to begin something if it was likely to soon end. They felt that the experience of receiving a positive form of support for a short period, only to have it abruptly taken away, could be more damaging than not having the support in the first place.
- Lived experience of disability. Individuals said that they would want a support worker to be somebody with a clear understanding of how unpredictable living with a disability can be, and how much it can impact individuals in ways that would be hard to understand had you not lived through it yourself. Participants with hearing impairments said that if the support worker didn't understand hearing impairment to a sufficient extent that they could tailor their support in a way that was very specific to the experiences of deaf people, then they thought it wouldn't be worthwhile as a support concept.

'If I was to do [the support worker concept] ... I would like to know that someone [out there] with sixteen years work experience or someone with a certain amount of experience, have experienced people with Autism, ADHD, mental health, I would like to be able to talk to someone who knows. Not someone I tell something and they look at me and think I'm stupid, do you know what I mean?'

(Female, 25+, focus groups)

- **Trust and confidentiality**, with some individuals noting that it would be important for them to be able to trust that the support worker would keep confidential information to themselves. A key concern about unfamiliar individuals in the support worker role was that they might have to refer information about the individual on to other authorities, which felt like being 'grassed on', resulting in private details 'being on file'.
- Location, with individuals saying that they would ideally be able to choose where
 interactions with support workers happened. Many said that, at least at first, they
 would prefer to meet in familiar, neutral spaces, such as a chosen local café;
 they were unsure about the support worker visiting them in their own homes
 due to concerns about finding this intrusive, and needing to build trust first. No
 individuals thought that a JCP office would be a good place to meet support
 workers, as this was felt to be a noisy, anxious, disrupted environment.

For some, especially younger participants, the interest in the support worker concept was related to a desire for holistic support that addressed wider issues such as debt,

housing problems, and applying for and claiming benefits. They felt that specific employment-related support would only truly be helpful if it was combined with this more holistic support. This interest was informed by positive experiences of 'help with life admin' from support workers and organisations such as a homeless shelter and Hastings Works (a careers and recruitment social enterprise). It also tied in to building confidence and self-esteem, and the ability to cope with day-to-day life.

The focus groups thus highlighted the importance not just of what is offered, but also how it is delivered. It was important that support providers were able to work with individuals intensively for a sustained period to allow trust to develop. This was important to all, but particularly so for younger people with mental health conditions.

5.4 Awareness of and interested in the current DWP/JCP support offer

In the focus groups (which were conducted with claimants in the ESA Support Group with at least some interest in paid work), participants were given a presentation by a Disability Employment Advisor (DEA) summarising the support available from JCP, including via local partners; and describing the process and expectations if individuals were to access support.

Claimants' prior awareness of the support available, and of the disability expertise among some JCP staff, was low. Participants had generally not heard about the support previously, as their contact with JCP had been very limited.

'I've learned more today than [the whole previous time spent on ESA]. And I've been on ESA since 2012. She answered questions I've been asking for two years.'

(Female, 25+, focus groups)

Claimants with a more strongly negative perception of DWP/JCP did not fully engage with what was presented to them, even if in theory they valued its content, as they believed there was a hidden agenda and were highly sceptical.

'If you do take up any of those things, are they not going to try and push you towards [the WRAG group] or affect your benefits?'

(Female, 18-24, focus groups)

Others, however, responded more positively to the presentation, particularly in relation to the 12-week linking period; permitted work; and Access to Work funding.

When they were asked who they would trust to deliver employment-related support, in the context of their disability or health condition, some individuals trusted voluntary sector organisations that they felt had a good understanding of their conditions and the need for flexibility. Others trusted NHS staff, for example GPs and specialist doctors. As mentioned in section 5.3, some individuals were uncomfortable about the idea of the employment-related support being provided by DWP or JCP, and wanted it to be provided by trusted parties such as charities. Others, however, did not express such reservations.

Views on the 12-week linking period

The 12-week linking rule protects ESA claimants' benefit for breaks of up to 12 weeks, which means someone who becomes sick again within 12 weeks of leaving ESA may be able to re-qualify for a further 365 days of ESA.

None of the participants in the focus group had heard about the 12-week linking period prior to being presented with it, but, when told about it, they were generally positive about the 12-week linking period. Those with more work experience, however, felt it was not long enough. They argued that settling into a new job takes far longer than 12 weeks, and that the linking period would need to recognise the possibility of fluctuating health conditions. For example, individuals could think of examples of job roles undertaken during the summer months that would be very challenging during the colder winter months due to seasonal fluctuations in their condition and said the linking period would need to be long enough to reflect this. While some suggested a period of six months others felt 12 months was a more appropriate period.

Views on permitted work

People claiming ESA can do permitted work without it affecting their benefit. It is permitted work if: (a) claimants earn up to \pounds 125.50 a week; and (b) claimants work less than 16 hours a week.⁴⁸

In the focus groups, claimants were also largely positive about permitted work, particularly that it allowed them to earn without reducing benefit payments and that it also applied to self-employed work, but expressed concern at the possibility of it impacting housing benefits.⁴⁹ For a few however, the realisation that they would be able to try working and to top up their benefit payment was a motivating factor:

'The fact that I now know I can work a few hours without worrying means that I've got a bit more drive to start thinking about what I can do.'

(Female, 25+, focus groups)

Views on Access to Work

Access to Work (AtW) is a publicly funded employment support programme that aims to help more disabled people start or stay in work, by providing practical and financial support with help or adaptations that go beyond the reasonable adjustments that employers are required to make under the Equalities Act 2010.

While some claimants in the focus groups were positive about Access to Work, others believed the funding was in reality very difficult to obtain and that the scope for what it would fund was very narrow. Some questioned the definition of reasonable adjustments, which are expected to be covered by the employer, as their experience

⁴⁸ In Universal Credit (UC), claimants who have a health condition or disability and have had their Work Capability Assessment receive a Work Allowance: those who receive money to help with their housing costs can earn up to £287 per month without it affecting their UC payment; and those who do not receive help with their housing costs can earn up to £503 per month before earnings are deducted from their benefit award. UC claimants are not restricted on the number of hours they work to make up those earnings.

⁴⁹ For claimants receiving Income-related ESA, earnings from permitted work have no effect on Housing Benefit. For claimants in receipt of Contributions-based ESA and Credits only cases, permitted work earnings may affect Housing Benefit and claimants are advised to check with their local authority before undertaking permitted work.

suggested employers would not be willing to fund these. One group believed schemes such as Access to Work would be cut as soon as Universal Credit came into full effect and therefore did not think it was a credible offer.

6 Perceptions of and communication with DWP and JCP

This chapter considers Support Group (and UC equivalent) claimants' perceptions of the Department for Work and Pensions (DWP) and Jobcentre Plus (JCP). It also covers attitudes towards contact from DWP and JCP, as well as claimants' preferred frequency and mode of communication. Findings come from both the qualitative and quantitative stages of the research.

6.1 Perceptions of DWP and JCP

This section is based on the qualitative stage of the research, drawing on the focus groups and in-depth and peer interviews. Opinions were divided in the focus groups and interviews regarding whether the DWP and JCP were distinct and different or the same entity. Both tended to be seen in a negative light although the extent of this varied: views were often more moderate when the claimant had developed a more trusting, supportive relationship with an individual JCP advisor.

6.1.1 More positive views and experiences

The specific positive experiences that these claimants recalled, encompassed the JCP advisors being kind and compassionate; having a good understanding of the individual's health condition; listening to the individual's needs and wants and tailoring the advice and support accordingly (rather than 'pressuring' the individual to apply for roles that felt inappropriate).

One claimant mentioned in the focus groups that they thought the advisors they had spoken to since moving onto ESA 'were very kind and considerate and helpful'; another had been, for a period, in the Work Related Activity Group, and had an 'absolutely lovely' advisor. She noted that this advisor's area of expertise seemed to be working with mental health conditions, rather than physical disabilities, and so he had a good understanding of how her mental health condition affected her.

'There was a guy...he was absolutely lovely because he'd had experience with not the physical side but the mental health side of things.'

(Female, 25+, focus groups)

One claimant in the in-depth interviews listed a work coach at JCP as a 'trusted individual' who had provided support tailored to his needs, without inappropriate pressure. This work coach had helped him with sorting out his Universal Credit claim and had spoken to him about the kinds of jobs he might want to do in future. Another claimant had received useful advice about the kinds of voluntary work and courses

he could do to improve his CV. The work coach was understanding, knowledgeable about benefits and employment advice, took an interest in the claimant's condition, and pointed him in the direction of different websites/resources that he could use.

'He understood what I was going through ... I used to ask him questions and he always seemed to know the answers.'

(Male, 45-54, in-depth interviews)

However, even where there were positive experiences of advisors, some claimants complained about an inconsistency between different advisors or other members of staff at the DWP/JCP: they felt a message from one individual would not always be adhered to by the next person they spoke to, leading to an impression of untrustworthiness.

6.1.2 Less positive views and experiences

The more negative perceptions of DWP and JCP were often linked to a perceived underlying agenda of making cost savings and benefit cuts. In several cases, individuals had previously received sanctions (before entering the ESA Support Group), which strongly reinforced this impression and made it hard for such individuals to think of the DWP or JCP as anything other than punitive agencies. More negative attitudes were also connected to claimants' previous experiences where they felt their circumstances had not been dealt with sensitively, ranging from being asked to climb up a staircase at a JCP office while using crutches, to being asked about personal matters in a manner felt to be insensitive.

Experiences of Work Capability Assessments (WCAs) contributed to these negative views, even when individuals knew that these were carried out by separate contractors. Some claimants likened their experiences of WCAs to court appearances, felt they were not believed by assessors and that assessors demonstrated a limited understanding of the specifics of their situation (particularly in relation to mental health conditions), and reported that the stress caused by the experiences had a negative impact on their mental health.

Some claimants took these negative experiences to indicate a lack of understanding by the DWP and JCP of disability in general and mental health problems in particular. One claimant with depression recalled being told that she 'seemed in a good mood today' when they came in to see an advisor, a comment which she perceived as questioning the reality of her condition. Other claimants felt that JCP advisors they had interacted with had shown an old-fashioned understanding of mental health, focused on taking individual responsibility for one's predicament.

'[They should] bring themselves out of the 1940s; stop telling everyone to have a stiff upper lip ... There are limits to that. And it's not going to take a lot to put some people back on their backside.'

(Female, 25+, focus groups)

A few claimants felt this lack of understanding of disability on the part of the DWP/ JCP was hindering the DWP's/JCP's ability to successfully help people into work. One person with a hearing impairment thought JCP advisors were harming their search for work by putting them forward for jobs that didn't match their skills and qualifications, due to an inaccurate understanding of the impact of their disability on their working

capacities. Others were concerned that JCP were not sufficiently focused on finding individuals employment appropriate to their skills, ambitions, abilities and their condition, because of a perception – often derived from interactions with JCP prior to their joining the Support Group –that JCP were trying to 'push' individuals towards whatever jobs were available.

In both the focus groups and in-depth interviews, some claimants also expressed concern about the aforementioned 'agenda' they suspected was underlying any DWP offer of support. They viewed the DWP as primarily concerned with cost cutting and benefit reductions, rather than with helping claimants manage their condition and find suitable work. They therefore had misgivings that any purported offer of support would in fact be driven by an underlying desire to take benefits away. A few claimants in the in-depth interviews believed that JCP offices had 'sanctions targets'. This meant that some individuals found it difficult to engage with the thought of a DWP support offer: even if they were attracted to the offer in theory, they couldn't imagine it being delivered 'without strings attached' by either the DWP or JCP.

'Once you've replaced all the Job Centre staff's attitude with a positive, can do attitude that will help you, which won't put [down your] mental health, that's step number one. Your trust, that's going to take years and years and years.'

(Female, 25+, focus groups)

The peer-to-peer interview participants also tended to have a negative view of the DWP and JCP, although despite this a few were very keen to receive support with finding a job that was suitable for them.

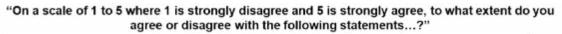
6.2 Attitudes towards contact from DWP and JCP

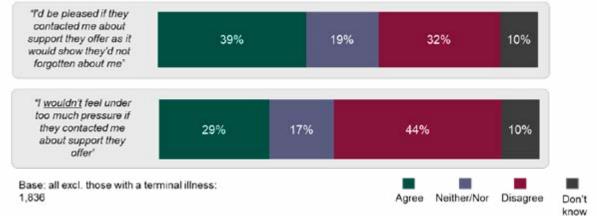
6.2.1 Quantitative findings on attitudes towards contact

In the survey, claimants who were not terminally ill were asked how they would feel if DWP/JCP contacted them about the support they offered.

Four in ten (39 per cent) said they would be pleased if DWP/JCP contacted them about the support they offer; and three in ten (29 per cent) said they wouldn't feel under too much pressure if DWP/JCP contacted them. At the same time, over four in ten (44 per cent) reported that they would feel under too much pressure if DWP/JCP contacted them (Figure 6.1).

Figure 6.1: Attitudes towards contact from DWP/JCP





The shorter the time claimants had been on out of work benefits, the more likely they were to welcome contact from JCP and DWP: over half (52 per cent) of claimants on out of work benefits for less than a year said they would be pleased to be contacted about support, versus 39 per cent overall.

Even among those who said their condition or disability ruled out paid work, over a third (35 per cent) said they would be pleased if JCP and DWP contacted them about support, indicating levels of openness to contact even among those who are furthest away from working.

6.2.2 Subgroup analysis

Broadly, the survey findings across the subgroups were in line with expectations, with individuals who were considering work as a possibility in the near future more likely to welcome contact and less likely to find such contact pressurising. For example, only 34 per cent of those who said they would be able to work in the near future agreed that they would find contact pressurising, versus 44 per cent overall; and 50 per cent of those who felt they would be able to work at some point in the future agreed they would be pleased to be contacted about support, versus 35 per cent of those who said they work again.

Black and Minority Ethnic (BAME) claimants were more likely to welcome contact from JCP and DWP (51 per cent of BAME claimants agreed they would be pleased to be contacted about support, versus 38 per cent of white claimants).

Individuals with internet access and confident or expert internet skills were also more likely to welcome any contact from DWP or JCP, indicating a correlation between internet skills and work-readiness (also noted in sections 2.3.2 and 5.2.2).

Claimants aged 18-24 were more likely to strongly disagree, and less likely to strongly agree, that they'd feel under too much pressure if DWP or JCP contacted them about support. Conversely, 50+ year olds were more likely to strongly disagree that they would be pleased to be contacted about support, and less likely to strongly agree that they they would be pleased to be contacted.

There were no significant differences between Universal Credit (UC) and Employment and Support Allowance (ESA) claimants, once time on benefits had been taken account of.

6.2.3 Qualitative findings on attitudes towards contact

Among those with at least some interest in working, in the focus groups, there was an appetite for communications from the DWP or JCP regarding the employment-related support available. Some even spontaneously requested more information about what support is available before the issue was raised in the group discussion.

Some claimants in the focus groups felt sad and frustrated by the lack of communication about available support, as it implied they had been overlooked, and complained that no employment-related support or engagement had been offered to them at all.

'ESA Support Group – I thought it meant what it said on the tin. I thought it meant a support group – I didn't think it meant you don't exist ... it's quite unbelievable.'

(Female, 25+, focus groups)

Others, however, had more strongly negative views of DWP/JCP and were happy not to hear from them again, as they found such communications stressful.

Given the sometimes-fraught relationships claimants had with DWP/JCP, it was thought important that communications were carefully worded to make it clear there was no pressure to take up the support; some also suggested making it clear that JCP's approach to working with people with disabilities has changed, to address previous negative interactions head-on. Some individuals – particularly those with mental health conditions – recommended that disability experts input into the content of communications to make them more reassuring and accessible.

Claimants also thought it was important to differentiate any communications about employment support from letters about benefits entitlements, which some found alarming. There was no clear consensus about who the communications should come from, although on balance the DWP was seen as slightly more neutral than JCP (which, despite its local credentials, was more loaded with negative connotations); and an entirely new brand or third-party organisation was preferable to either.

6.3 Frequency and mode of communication from DWP and JCP

When claimants were asked in the survey how often they felt it was appropriate for DWP or JCP to contact them about the support on offer, six in ten (62 per cent) were open to contact from DWP and JCP, while three in ten (29 per cent) preferred never to be contacted. Among those open to contact, once every 6-12 months was the most commonly preferred frequency of contact (Figure 6.2).

There was a clear preference for 'traditional' means of communication, with claimants overall and nearly all subgroups choosing letter and phone call respectively as their first and second preferred means of communication.

UC claimants were more likely than recent ESA claimants to welcome communication via text (50 per cent of UC claimants, versus 36 per cent of recent ESA claimants) and email (47 per cent versus 32 per cent), arguably reflecting UC's online application and management process.

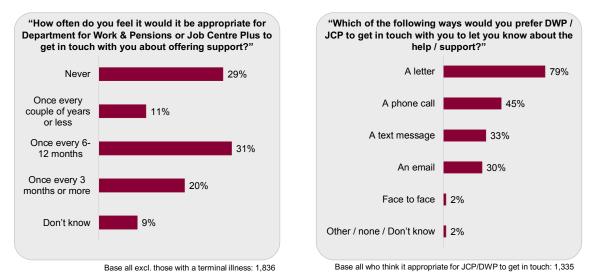


Figure 6.2: Preferred frequency and mode of communication from DWP/JCP

Similarly, in the focus groups, claimants' preferences for frequency and mode of communication were varied; however, the broad consensus was that communications repeated at regular intervals would be necessary so that at least some of them landed at a time when the individual felt well enough to engage with them.

'People need time to let it sink it in. Put the information everywhere you can – in the internet, posters, pamphlets, give us a booklet when we sign in.'

(Female, 25+, focus groups)

6.3.1 Subgroup analysis

Frequency of contact

Claimants in the first year of their claim were more likely to welcome very frequent contact, of once every 3 months or more: nearly half (43 per cent) of those on benefits for less than a year said they would welcome this, versus a fifth overall. This was also the case for 18-24 year olds, with a quarter (25 per cent) welcoming contact once every three months or more.

In line with expectations, those who expected their condition to improve (86 per cent) and those who felt they might be able to do paid work in the near future (91 per cent) or later than two years (83 per cent) were more likely to find contact appropriate.⁵⁰

Claimants with mental health conditions (70 per cent of those with a mental health condition as their main condition and two-thirds of those with any mental health

⁵⁰ I.e. they did not say such contact would 'never' be appropriate.

condition) were more likely to find contact appropriate, again perhaps reflecting a greater appetite for help/support among this group of claimants.

Those on out of work benefits for a shorter period of time were more likely to find contact from DWP and JCP appropriate (73 per cent of those on benefits for under a year, and 76 per cent of those on benefits for 1-3 years, versus 62 per cent overall), while those on benefits for over ten years were less likely to find contact appropriate (52 per cent).

Those who said it would 'never' be appropriate for DWP or JCP to contact them were more likely:

- To have long lasting conditions (32 per cent of those who expected their condition to last for the rest of their life said it would never be appropriate, versus 29 per cent overall);
- To have never been in paid work (39 per cent of those who had never been in paid work said it would never be appropriate);
- To be aged 50+ (31 per cent of those who were aged 50+ said it would never be appropriate); and
- To have no qualifications (38 percent of those with no qualifications said it would never be appropriate).

There were no significant differences in preferred frequency of contact between UC claimants and recent ESA claimants.

Mode of communication

Differences in mode of communication were broadly in line with expectations: those with a home computer were more likely to welcome email communication (40 per cent, versus 30 per cent overall), as were those who were confident/expert internet users (50 per cent). Those with mobiles as their primary source of internet access were more likely to welcome text messages (44 per cent, versus 33 per cent overall).

7 Segmentation

Throughout this report we have discussed the profile of claimants, their health condition, benefits and work history, their routes into the Support Group and their attitudes towards employment, employment-related support and to communication from the Department for Work and Pensions (DWP) and Jobcentre Plus (JCP). The analysis has been one or two dimensional, looking at responses to single questions or sets of questions at a time, and considering sub-group analyses at the level of "observable differences" between claimants (i.e. in terms of their known characteristics such as their health condition, other demographics and closeness to paid or voluntary work). This chapter explores a more advanced form of analysis known as segmentation, which looks at key areas in combination with each other, in multiple dimensions.

7.1 The process

Put simply, segmentation involves the use of a statistical programme to examine A) responses to a selection of questions 'at once' and B) group respondents together according to similarities in said responses.⁵¹ The questions that were included in the segmentation were those that provided an indication of claimants' closeness to paid work (i.e. their attitudes towards and feelings about whether they could enter paid work in the future), the perceived barriers that they face in entering paid work and the various forms of support that they said they might be interested in to help them move closer to paid work (as explored earlier in Chapters 4 and 5).

Four groups of claimants were excluded from the segmentation analysis, leaving 638 claimants included. The groups excluded were:

- Claimants who reported that their health condition rules out paid work, and who therefore could not be asked questions about barriers and support options: 1,134 individuals
- Claimants who reported that their condition was terminal, who again could not be asked questions about barriers and support options: 176 individuals
- Claimants who reported that they were already in work: 42 individuals
- Claimants who did not give a sufficient level of response to the barriers and support questions, in that they repeatedly selected a non-response option, such as "neither agree nor disagree", "don't know" or "refused": 22 individuals

⁵¹ In this case, we have used Latent Class Analysis. More information about this can be found in the Technical Appendix.

7.2 Introducing the segments

The segmentation analysis produced six distinct segments. These were given names designed to reflect their closeness to paid work and attitudes toward perceived barriers and support offers. They are outlined in Figure 7.1 below, along with two further groups; those who reported that their health condition ruled out work as an option both now and in the future and those who reported being in paid work already. The percentages in this chart are therefore based on the following population, in order to create as complete a picture as possible of the population of claimants in the ESA Support Group and UC LCWRA group:

- Those who made it into the segmentation: 638 individuals
- Those who report that their health condition rules out paid work: 1,134 individuals; and
- Those who reported that they were already in work: 42 individuals.

The figure shows that those who say their "condition rules out paid work" are the largest group in the reported population, with almost two-thirds (65 per cent) falling into this category. This is the same 65 per cent discussed in section 4.1 (see Figure 4.1).

The base sizes of each segment are also shown in Figure 7.1. As this shows, the 'No interest in help, desire to be left alone' group is the smallest segment, based on 27 claimants in total. Results among this group should therefore be treated with caution. Indeed, the differences noted among this group are not statistically significant, but instead represent any deviation above or below the average by at least 5 per cent. These differences have been included given the clear patterns that emerge, and in the interests of creating a more complete picture. This fact is made clear throughout this chapter.



Two of these segments, equivalent to 12 per cent of claimants, were the closest to work:

- *Work ready* (four per cent of claimants). These claimants were more strongly interested in returning to work; felt it would benefit their health; were more interested in work-related support; and saw fewer barriers. They felt they could return to work immediately, if they found the right job and with the right support.
- **Interested in support** (eight per cent). These claimants were most interested in work-related support, and their barriers were more focused on knowledge, skills and confidence, and less on health.

A further two segments, together equivalent to 10 per cent of claimants,⁵³ had an interest in work but saw it as something that could be possible in the further future:

- Interested in support, but other things to sort first (seven per cent). These claimants were interested in work-related support, but were more likely to have personal or family issues such as debt, housing issues, or caring responsibilities. They were also more concerned than those in other segments about their health, both as a barrier to finding a job, and in terms of work making it worse.
- Equipped, but need time (four per cent). These claimants were equipped in terms of their knowledge, skills, confidence; in having support for their health condition(s); and not having other family or caring responsibilities. However, they were more likely to say that work could be a possibility in the more distant future (in two or more years' time). The fact that this group needs more time before they enter into employment is possibly related to the type or severity of condition(s) they reported or a general apprehension about the impact of their condition on their ability to work and the impact of work on their condition. Indeed, they have a poor health score and are more likely to report concerns about how their health condition will interact with work.

Two segments, equivalent to 10 per cent of claimants, had least interest in paid work:

- **No interest in help, worried/unsure** (nine per cent). These claimants were least interested in help and reported the most barriers to working; and they either had no interest in returning to work or were most unsure about doing so.
- No interest in help, desire to be left alone (one per cent). These claimants were most likely to say they were not at all interested in work, and less interested in work-related support. This lack of interest in work aside, their only barriers were a lack of belief that employers could accommodate their health, concerns that work would be detrimental to their health, and uncertainty about how to present themselves in CVs and interviews. While these claimants wouldn't feel under pressure if they were contacted by DWP or JCP, they wouldn't be particularly pleased either and more often said that DWP/JCP should never get in touch.

⁵³ Note that the four segments that are closer to work sum to slightly more than the twenty per cent who had some desire to do paid work in future (see Figure 4.1). The reason for this is that the segmentation draws on a wider range of questions before allocating an individual to a segment – so, for instance, an individual who was less interested in work could be allocated to one of the 'closer to work' segments because of their other characteristics (interest in sources of support or barriers to employment) made them a better 'fit' with that segment. The proportion that desires to work and the proportion accounted for by the four 'closer to work' segments are therefore similar, because the segments reflect closeness to work, but not identical, because the segments also factor in other characteristics too.

7.3 Exploring the segments

The next section of this chapter profiles each segment in turn. It describes in more detail how each segment is defined. It also describes their specific health conditions; other demographic characteristics; work and benefits history; support needs; degree of digital engagement and attitudes and preferences regarding receiving communication from DWP/JCP about employment-related support. Please note that:

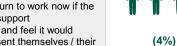
- Each chart shows the characteristics/attitudes/interests that each group is more likely to demonstrate. This does not mean that everyone in the group demonstrates all of these traits.
- Each chart indicates the health score for each segment. Asterisks indicate cases where the health score is significantly different from the average.
- Charts 1-6 describe the characteristics of the segments, relative to each other. Chart 7 describes the characteristics of those who have ruled out paid work on the grounds of their health, relative to the full sample of respondents.
- The findings on Chart 6 should be treated with caution, as the base size for the "no interest in help, desire to be left alone" group is small (27 respondents). This means that the majority of the differences shown are not statistically significant, but instead represent any deviation above or below the average by at least 5 per cent. These differences have been included given the clear patterns that emerge, and in the interests of creating a more complete picture.

Segmentation Chart 1

Work ready

Definition

See fewer barriers and feel they could return to work now if the right job was available and with the right support



More strongly interested in return to work and feel it would benefit health, that they know how to present themselves / their conditions in CVs / at interviews and that employers could accommodate their needs

Health condition

Less day-to-day impact, more <u>positive health sc</u>ore & prognosis

- More likely to be musculoskeletal (MSK) conditions (legs and feet=main)
- Moderate health score (0.5*)
- · Less likely to be issues with mobility
- Typically developed at birth
- More likely to feel conditions will improve
- More likely to last for <1 year

Work and benefits history Consistent labour market activity

- Mostly been in paid work & worked recently (6-12 months ago) or at least more recently than others (more likely 5-10 years ago & less likely 15+ years)
- More likely to have been in part-time paid work (up to 15 hours per week)
- Typically claiming for less time (<1 yr)
- More likely to be currently volunteering

Barriers to work *Fewer perceived barriers to work*

 Less likely to feel barriers to work apply (all except 'I am worried I wouldn't get my benefits back' and 'other personal/family issues')

JCP / DWP contact - frequency and mode

Open to very frequent contact, prefer digital contact

- More open to frequent contact (once a month or more than once a month)
- Less open to contact through letters, more open to contact via email

Other demographics

- More likely to be renting: specifically paying rent to relatives / friends or have shared ownership
- More qualified, as more likely to have a Level 5 qualification

Support and digital engagement More likely to have work-related support, digitally engaged

- More likely to have work-related support
- More connected to the internet (home and outside of home, both regular and irregular)
- More confident using the internet (though not expert level)

Support offers

More interested in practical support with finding suitable employers and roles

 More likely to be interested in help with finding suitable work and employers; advice/guidance about what sort of job they could do; and help finding volunteering opportunities or voluntary work/experience

JCP / DWP contact - Reaction Most positive

 Wouldn't feel under too much pressure if they were contacted

Segmentation Chart 2

Interested in support

Definition

Health condition

cognitive conditions

(cognitive=main)**

discomfort

health score

The most interested in support

Less physical impact, more +ve

More likely to be mental health &

Less likely to be issues with pain /

- Main concerns are around knowledge, skills
- and confidence (less about health)
- Feel they might be able to work in near future (up to 2 years)



(8%)

Other demographics

- Younger (18-24), male
- Typically no dependent childrenMore likely to either own their property
- or live rent-free
 Less qualified (as slightly more entry level; fewer Level 5)
- Typically conditions developed when younger (birth/childhood)

Moderate health score (0.5*)

Work and benefits history Less labour market activity, but more recent activity where are active

 Unlikely to have worked before. Where have, have worked more recently (up to 5 years)

Support and digital engagement More likely to have work-related support, lower digital engagement

- No more/less likely to have *health-related* support overall, but where there *is* some, it is more likely to be from a carer, relative or friend
- More likely to have work-related support
- Typically not confident with the internet (feel unable to use it)

Barriers to work

Fewer perceived barriers to work

- More concerned about: not knowing what suitable jobs are available; not being confident in applying; not knowing how to present themselves/conditions in CVs/interviews; and not having the right qualifications, skills or experience
- Less concerned about most other barriers

JCP / DWP contact - frequency and mode

Open to relatively frequent contact, prefer digital contact

- More likely to feel that contact is generally appropriate, particularly every 6 months
- Less open to contact over the phone; although not internet confident overall, more open to email contact than phone

Support offers

More interested in practical support with finding suitable employers and roles

 More interested in a range of support, i.e. from a dedicated support worker, to resolve problems in a new job; in communicating health condition/support needs to employers; with finding suitable work/employers; advice/ guidance about what sort of job they could do; help finding voluntary work

JCP / DWP contact - Reaction Most positive

- Typically wouldn't feel under too much pressure if they were contacted
- Just over half would be pleased to be contacted about support, in line with the average for all respondents

**Mental health: psychotic disorder or Schizophrenia

**Cognitive: Asperger's / autism, learning difficulties, learning disabilities, ADHD.

Segmentation Chart 3

Interested in support, things to sort first

Definition

Interested in support but more likely to have personal or family issues such as debt, housing issues or caring responsibilities
Less concerned about skills/ knowledge, more about health

condition (both as a barrier and in terms of work making it worse) After the 'Work ready' group, most optimistic about returning to



(7%)

Health condition

Variety of conditions, impact broadly average

work either in the near or further future.

- More likely to be mental health, legs and feet, COPD**
- Poor health score (0.4)
- Less likely to be issues with self-care
 Typically conditions developed in adulthood

Work and benefits history More varied labour market activity and less recent

- Tend to have been in paid
 employment
- Tend to have been out of work for longer (less likely to have been in work within the last 5 years)

Barriers to work

More concerned about personal/family issues and caring responsibilities; being 'unemployable'

 More concerned about personal/family issues and caring responsibilities; being 'unemployable' due to age or health condition; or not getting their benefits back

JCP / DWP contact - frequency and mode

Less preference for digital contact

 Less open to communication via email, slightly more open to face-toface communication

Other demographics

- Less likely to be aged 18-24, more likely to be aged 45-49
- Typically have dependent children
- Less likely to own property
- More qualified, as more likely to have a Level 5 qualification

Support and digital engagement Digitally engaged

- No more/less likely to have support (health or work-related)
- Typically a confident or expert internet user

Support offers

More interested in support with other issues such as debt, managing <u>finances or ho</u>using

 More interested in support with other issues such as debt, managing finances or housing; help with the costs of starting work; help communicating health condition/support needs to employers; help understanding disabled people's rights to do with working

JCP / DWP contact - Reaction Fairly positive

 Moderately likely to feel under pressure if contacted

**Mental health: Depression, OCD, borderline personality disorder. For reference, COPD refers to "Chronic obstructive pulmonary disease".

Segmentation Chart 4

Equipped, but need time

Definition

- Equipped in terms of knowledge, skills, confidence and support with health condition and absence of caring / family responsibilities
- More likely to state currently unable to work, but feel they might be able to in future (2+ years, rather than 1 year)



(4%)

Health condition

Variety of conditions, more day-to-day impact, less +ve health score

- Typically a range of conditions (cancer, bowel/stomach/liver/kidney/digestion =main)**
- Poor health score (0.4*)
- More likely to be issues with mobility, usual activities, pain or discomfort
- Less likely to fluctuate
- Unlikely to have developed in childhood

Work and benefits history Consistent labour market activity

Mostly been in paid employment

More concerned about fluctuating

· More concerned about the impact of

Despite lower incidence of fluctuating conditions, more concerned about their health fluctuating too much to work

JCP / DWP contact - frequency

Tend to desire less frequent contact

(every couple of years of less)

Less open to frequent contact

their health on travelling to work; employers not accommodating their health needs; or a job not benefiting

conditions, and how health will

Barriers to work

interact with work

their health.

and mode

Support and digital engagement *More medical support, digitally engaged*

Other demographics

Tend to be older (50+)

Typically no dependent children

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- Have the most *health-related* support in place, and this is more medically focused (GP, hospital, specialist medical support and clinics)
- Less work-related support in place
 More connected to the internet, but
- only through irregular accessMore internet-confident (expert-level)

Support offers

· Responses are in line with the average

JCP / DWP contact - Reaction Standard

· Responses are in line with the average

**Range: range of MSK and other long-term conditions; fatigue or problems with concentration

Segmentation Chart 5



Segmentation Chart 6

No interest in support, desire to be left alone

Definition

- Most likely to say not at all interested in work, less interest in support
- Report fewer barriers, main ones being: lack of belief that employers could accommodate their health needs; feeling that work would not be beneficial to their health; and that they would be unsure how to present themselves/condition in a CV interview Wouldn't feel under pressure from DWP / JCP contact but
- wouldn't be particularly pleased either more often say they should never get in touch

Health condition

Less day-to-day impact, tending to stay the same

- Typically a range of conditions; often unable to distinguish main condition**
- Moderate health score (0.5)
 Less likely to have issues with
- mobility, usual activities, anxiety and depressionTypically developed in adulthood
- Tend to say will stay the same

Work and benefits history Less labour market activity, different working style

- Unlikely to have worked before. Where have, this was more likely to be 5-15 years ago, and selfemployment or part-time work (up to 15 hours per week)
- Typically claiming for less time (1-3 years)
- Have volunteered in the past

Barriers to work

More concerned about how to present themselves/their condition, <u>and how health will interact with work</u>

- More concerned about not knowing how to present themselves/their condition in CVs/interviews; employers not accommodating their health needs; or a
- job not benefiting their health

 Less concerned about all of the other barriers to work

JCP / DWP contact - frequency and mode

Less open to contact, mixed preference on mode

- More likely to feel contact would never be appropriate
- Less open to contact through letters, more open to communication over the phone and email

Other demographics

 Tend to be in the youngest (18-24) or oldest (50+) age band

(1%)

- Typically have dependent children
- More likely to own property
- Less qualified

Support & digital engagement Informal health-related support, more work-related support, mixed digital engagement

- No more/less likely to have *health-related* support overall, but where there *is* some, it is more likely to be from a carer, relative or friend
- More likely to have *work-related* support
- More connected, but via mobile phone

Typically lower internet confidence

Support offers Among the least interested in support

 Less likely than average to be interested in: support from a dedicated support worker to resolve problems in a new job; help with the costs of starting work; help communicating condition/ support needs to employers; help understanding disabled people's rights; wider support with other issues

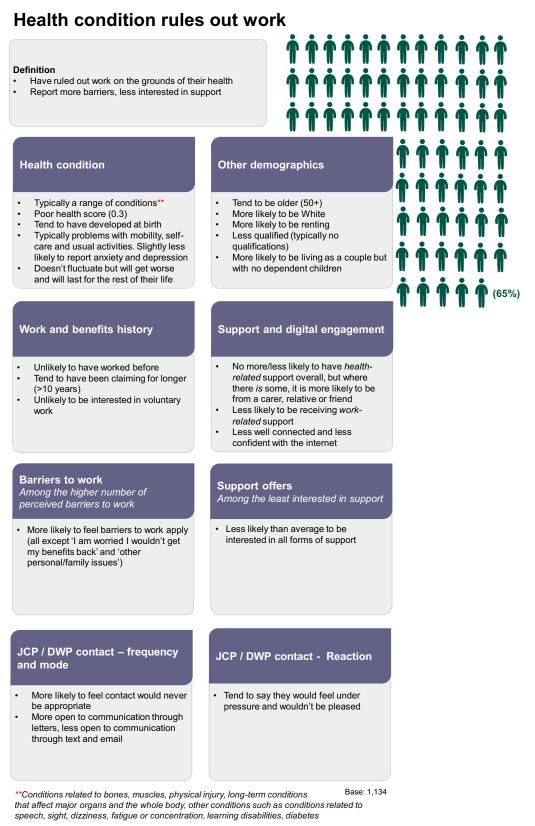
JCP / DWP contact - Reaction Negative

 Tend to say they would not feel under pressure if contacted but wouldn't be pleased either

**Range: Agoraphobia, Neck and shoulders, heart / blood pressure, chest or breathing, fatigue or concentration, dizziness and balance, epilepsy, migraine, ME, Other

Segmentation Chart 7

This chart describes the characteristics of those who have ruled out paid work on the grounds of their health, relative to the full sample of respondents.



In the final sections of this chapter we explore the specific barriers to paid employment and the various forms of future employment-related support that applied to each of the segments, to highlight the key patterns.

7.3.1 Barriers to work by segment

Figure 7.2 shows the extent of agreement with each of the barriers across each of the six segments. The cells highlighted in red denote agreement levels that are higher than the average i.e. where barriers are more strongly felt; and those in green show the opposite, i.e. agreement levels lower than the average and therefore where barriers pose less of an issue.⁵⁴ Observing these colours, it is quickly evident that the "*work ready*", "*equipped, but need time*" and "*interested in support*" segments saw fewer barriers to paid work on average (3.3, 5.9 and 6.6 respectively) and the "*no interest in support, worried/unsure*" saw the most (9.5 on average).

The table also shows that the "*equipped but need time*" group are differentiated by concerns about fluctuating conditions, employers not accommodating health needs and about a job not benefiting their health; while the "*interested in support, things to sort first*" group are differentiated by concerns about their age, personal/family issues and caring responsibilities, as well as fears about not getting benefits back and about their health condition making them unemployable.

⁵⁴ The base size for the 'left alone group' is small (27 respondents). This means that the majority of the differences shown are not statistically significant, but instead represent any deviation above or below the average by at least 5 per cent. These differences have been shown given the clear patterns that emerge, but should be treated with caution.

Figure 7.2: Barriers by segment⁵⁵

										Less likely than avg.	at least 5%, not sig)	More likely than avg. More likely than avg.	(by at least 5%, not sig)	Base: 638, 77, 162, 122, 89, 161,	27 Differences for group 6 are +/- 5	percentage points vs. avg, but not statistically significant
Left alone	31%	10%	15%	14%	<1%	19%	69%	11%	73%	69%	14%	11%	<1%*	4%	6%	3.5
Worried / unsure	88%*	91%*	93%*	92%*	86%*	43%	*%02	66%*	76%*	67%*	59%*	36%	37%	33%	13%	9.5*
Equip. need time	91%*	÷%09	*%77	64%	25%*	31%*	16%*	30%*	54%*	53%*	36%	15%*	30%	4%*	<1%*	5.9*
Int. support, other 1st	20%	85%*	70%	66%	53%*	71%*	36%*	26%*	30%*	40%	39%	22%*	47%*	68%*	54%*	7.8*
Int. support	71%	71%	54%*	44%*	77%*	45%	59%*	65%*	24%*	13%*	20%*	61%*	32%	21%*	1%*	6.6*
Work ready	27%*	50%*	23%*	37%*	32%*	45%	13%*	18%*	8%*	3%*	10%*	16%*	19%*	28%	4%*	3.3*
AII	72%	74%	66%	63%	61%	47%	47%	46%	44%	39%	36%	34%	33%	32%	15%	7.1
	May find it difficult to travel to work due to condition	Worried people won't employ me because of condition	Condition fluctuates too much to work	Worried work could make condition worse	I don't feel confident about applying for jobs	I am worried that I wouldn't get my benefits back	DK how to present myself/condition in CV/Interviews	I don't know what suitable jobs are available	Don't think employers could accommodate health needs	Don't think a job would be beneficial to my health	Managing my condition means I don't have time to work	I don't have the right qualifications, skills or experience	Worried won't be employed due to age	Other personal/ family issues	Family/caring responsibilities	MEAN:

To what extent do you agree with the following barriers...?

The Work Aspirations and Support Needs of Claimants in the ESA Support Group and Universal Credit equivalent

⁵⁵ The three statements "Don't know how to present myself/condition in CV/Interviews", "Don't think employers could accommodate health needs" and "Don't think a job would be beneficial to my health" were previously phrased in the positive.

7.3.2 Support needs by segment

Figure 7.3 shows the extent of interest in each type of support offer across the six segments. The cells highlighted in green denote interest levels that are higher than the average, i.e. where there is greater interest in support, and those in red show the opposite; interest levels lower than the average.⁵⁶

This shows that the "*interested in support*" and the "*interested in support, things to sort first*" groups were interested in the most support types on average (4.2 and 3.9 respectively) and the "*no interest in support, worried/unsure*" and the "*no interest in support, desire to be left alone*" groups were the least interested (each 2.3).

It also shows that the two segments closest to work, i.e. "work ready" and "interested in support", were more interested in practical support with finding suitable employers and roles while "interested in support, things to sort first" group are differentiated by their interest in support with other issues in life such as debt, managing finances or housing, as well as help with disabled people's rights and the costs of starting work.

⁵⁶ Again, the base size for the 'left alone group' is small (27 respondents). This means that the majority of the differences shown are not statistically significant, but instead represent any deviation above or below the average by at least 5 per cent. These differences have been shown given the clear patterns that emerge, but should be treated with caution.

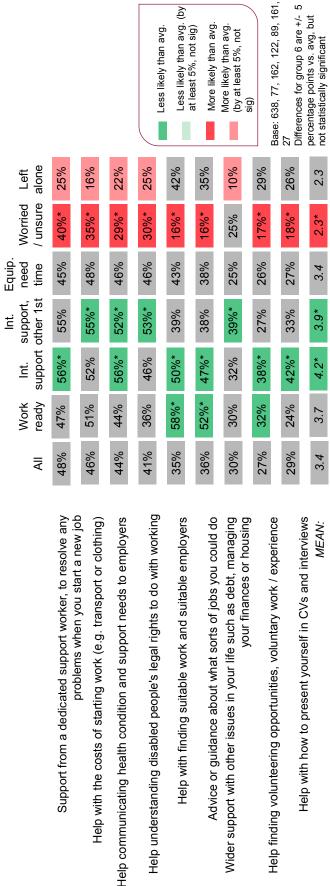


Figure 7.3: Support offers by segment

Help with how to present yourself in CVs and interviews

8 Conclusions

8.1 Understanding who is in the ESA Support Group and UC equivalent

The research found that claimants in the ESA Support Group and the Universal Credit LCWRA group tended to be older, less qualified and with limited digital skills and internet access, by comparison to the UK population overall. Their daily lives were shaped by the severity of their condition: this ranged from individuals with more manageable conditions who could fit their health needs into a routine alongside a range of other activities; to, at the other extreme, individuals whose conditions were harder to manage, and whose lives were dominated by health care needs. While the severity of impact(s) varied, the vast majority experienced some impacts on things like performing usual activities, self-care or anxiety and depression. These impacts could also be unpredictable, with two-thirds reporting fluctuating conditions. Most expected their health condition to last for the rest of their life and did not expect it to improve. Many of those with a mental health condition were not receiving mental-health related support.

The majority were also a long way from the labour market: consistent histories of paid work were relatively uncommon and previous paid work tended to be five or more years ago. Many had been on out of work benefits for a long time, typically for over five years.

8.2 Work aspirations

The majority of claimants have ruled out paid work as being a future option for them, predominantly on health grounds.

A fifth, however, did have a desire to do paid work, and more often it was part-time work that was of interest. Among these, four per cent of claimants thought they could work now if the right job was available and with the right support; overall, there was a fairly even split between those who felt paid work might be possible within the next two years and those who felt this might be possible in the further future.

A further two per cent were in paid work at the time of the survey; for the most part they were already doing the amount of work that they felt capable of or were comfortable with (mostly part-time hours).

Those interested in paid work tended to be closer to the labour market, with less severe health conditions and more recent experience of working; they also tended to be younger (under 50). The qualitative research showed they were often determined to enter work, with a strong work ethic being part of their identity.

Claimants – even those who felt closest to work – cited multiple barriers to entering work. Health-related barriers, such as health conditions making it difficult to gain or maintain employment, or working having a negative impact on health, were more prevalent than employment-related ones such as lack of qualifications, skills or experience.

8.3 Support needs

The findings show that, in seeking to meet the ambition of one million more disabled people in work, there is scope for DWP/JCP to engage with some claimants in the ESA Support Group and the UC equivalent to offer them voluntary support in their journey towards paid work.

Among those interested in employment, much of what claimants said they wanted in terms of support covers many elements already being offered or trialled by the DWP/ JCP, however, it emerged in the focus groups that claimants lacked awareness of what is available. Within the existing offer, there was particular interest in Access to Work funding, permitted work and the 12-week linking period (although some argued it needs to be longer than 12 weeks).

Four in ten claimants are open to the DWP/JCP communicating with them about the employment-related support on offer. This might take the form of communication every 6-12 months, setting out the support on offer (highlighting key appealing features such as Access to Work funding, permitted work and the linking period) and making it clear that there is 'no pressure' to take up this support.

Additional areas of support claimants wanted revolved around the concept of a dedicated support worker who would provide, for instance, in-work support to resolve any problems when starting a new job (also one of the most prevalent survey responses) and help with returning to benefits if work could not be sustained. Some claimants also wanted support with wider issues, including issues with housing, finances and debt, emphasising the importance of offering support that addresses claimants' needs holistically.

How support is delivered was also important. Claimants desired continuity of support over a sustained period of time, from someone with good interpersonal skills and lived experience of disability (or an in-depth understanding), to allow trust to develop. There was strong interest in the aforementioned 'support worker' concept as a way of delivering this. This also meant that claimants were hesitant to take up support where they thought this might only be on offer short-term (for instance, where they thought organisations might be closed down or have their funding withdrawn). Views were mixed on who might deliver this support: some individuals were uncomfortable about the idea of the employment-related support being provided by DWP or JCP, and trusted voluntary sector organisations that they felt had a good understanding of their conditions and the need for flexibility. Others, however, did not express such reservations.

The environment in which support was delivered mattered too: in the focus groups, many claimants initially wanted to meet a support worker in neutral spaces such as a local café, because they found the prospect of being visited in-home too intrusive. JCP offices were perceived to be noisy, anxious, disrupted environments; the consensus was that these were not a good place to meet a support worker.

There are specific groups of claimants who are particularly interested in support:

 claimants aged under 50 were more likely to see paid work as a possibility in future;

- those on out of work benefits for between one and three years were most likely to express interest in multiple forms of support, indicating that this may be a 'window of opportunity' for offering support, before being out of work becomes entrenched;
- the shorter the time that claimants had been on out-of-work benefits, the more likely they were to welcome contact from DWP/JCP about the employment-related support on offer.

Individuals with mental health conditions are another group who express greater interest: while they report the most barriers to employment, they are also more interested in all forms of employment-related support and more likely to believe that work would benefit their health. They were also more likely to be interested in wider support with issues in their life such as debt and housing, specifically.

Our statistical segmentation revealed further groups of claimants with specific characteristics and needs. This segmentation draws together claimants' closeness to paid work, the perceived barriers to paid work and the various forms of support they said they might be interested in to help them move closer to paid work, to create an overview of claimants in the ESA Support Group and UC equivalent.

This segmentation shows, for example, that the two segments that were closest to work ("*work ready*" and "*interested in support*") were more interested in advice or guidance about the sorts of jobs they could do, and practical support with finding suitable employers and roles. These segments are summarised in the diagram overleaf (Figure 8.1).



8.4 Challenges in delivering support

Supporting some claimants in the ESA Support Group and UC equivalent towards work will pose challenges in the following areas:

- The benefits system: currently the process of applying for benefits is experienced as highly challenging and emotionally taxing. Individuals feel their place in the ESA Support Group – and the financial and/or health-related stability that sometimes accompanies this – has been hard-won. Taking up paid employment is therefore seen as high risk; awareness of existing initiatives to de-risk paid employment (the 12-week linking period and permitted work) is low; and fear that engaging in work-related activity will trigger a WCA reassessment is common. The wider benefits system is thus perversely incentivising individuals in the ESA Support Group and UC equivalent to avoid engaging with work-related support.⁵⁸
- **Employer attitudes and behaviour:** individuals were concerned about how to find suitable roles and suitable employers, and how best to communicate their health condition(s) and needs to these employers. Those with previous experience of work were very conscious that the attitudes of their employer (and even their line manager) could 'make or break' an attempt to enter employment, and there was a general concern about whether employers would be understanding or flexible enough to accommodate their conditions and needs.
- **The DWP and JCP:** although four in ten claimants are open to the DWP/JCP communicating with them about the employment-related support on offer, nearly as many would rather be left alone. There is also a perceived credibility issue: qualitatively, it was common for individuals to associate DWP/JCP with a 'hidden agenda' of cuts; while previous negative interactions had often led individuals to believe that DWP/JCP do not have a sufficient understanding of disability. This means that, although much of the support claimants say they would like is already offered by JCP, a key challenge for DWP and JCP in engaging these claimants will be in overcoming the distrust that many claimants have in DWP/JCP.

⁵⁸ Some of this may be addressed by Universal Credit: as an in and out of work benefit it should provide a softer transition into work, although it would likely not address the fear that engaging in work-related activity will trigger a WCA reassessment. Our sample of individuals taking part in the qualitative research did not comment on the potential of UC to address their concerns.

Technical Appendix:

Annex A: Detailed methodology

In-depth interviews

A sample for the in-depth interviews was drawn by the DWP with potential participants sent advance letters explaining the purpose of the study and enabling them to opt out.

Advance letters were sent out to 1,425 claimants, of whom 16 per cent of individuals opted out of the research. Most did not give a reason for opting out, although a small number (15 individuals) opted out because they felt their health condition would prevent them from participating.

	Location	Bridgwater (UC)	Great Yarmouth (UC)	Cardiff	County Durham	London Borough of Newham	North Lanarkshire	Total
Pro	file	8	10	8	11	8	5	50
	18-24	2	3	2	4	1	0	12
Age	25-49	4	5	3	4	5	3	24
	50+	2	2	3	3	2	2	14
Gender	Male	5	5	4	5	4	2	25
Gender	Female	3	5	4	6	4	3	25
	Physical	4	6	4	4	5	4	27
Main health condition	Mental	3	4	4	6	3	0	20
condition	Other	1	0	0	1	0	1	3
Length of	Less than 12 months	8	8	2	1	0	0	19
time on benefits	12 months – 3 years	0	2	2	3	3	4	14
	3 years +	0	0	4	7	5	1	17
	ESA only	n/a	n/a	4	5	4	1	14
Claimant	ESA+ PIP/ DLA	n/a	n/a	4	6	4	4	18
type	UC only	4	7	n/a	n/a	n/a	n/a	11
	UC + PIP/ DLA	4	3	n/a	n/a	n/a	n/a	7
	Appointee	0	0	1	4	1	1	7
Appointees	Non- appointee	8	10	7	7	7	4	43
D	Employment	0	0	4	2	4	2	12
Route onto ESA59 (ESA only)	Incapacity Benefit	0	0	2	2	2	1	7
oniy)	Other	0	0	2	7	2	2	13
Perceived distance from work	Possibility of work in near future	0	2	1	1	2	1	7
	Possibility of work in further future	5	7	5	3	2	1	23
	Likely to never work again	3	1	2	7	4	3	20

Table A1: Completed interviews by area

⁵⁹ Information not available for those receiving UC (18 records)

Individuals had a wide range of conditions, but depression, stress or anxiety, and mobility problems were most common. Mental health problems were much more prevalent among those who were under 30 while physical conditions were present across all ages but were more common in those over 30. Many claimants aged under 25 years had received benefits for longer than 3 years.

Many participants said that they had more than one health condition. These individuals were asked to disclose all their conditions and then state their 'main' condition. Of those with physical and mental conditions, participants commonly reported their physical issue as their 'main' condition and often said that they developed a mental health problem while out of work because of a physical condition or disability.

Focus groups

Six extended (3 hour) focus groups were convened with individuals in the ESA Support Group who had not previously taken part in an in-depth interview. They explored in much greater detail the kinds of additional support that individuals might want with their health condition and/or with moving closer to work. A deliberative approach was also used for this element: a Disability Employment Advisor (DEA) from Jobcentre Plus (JCP) attended part of the discussion to tell participants about JCP's current approach to working with individuals with disabilities and health conditions, the types of support available from JCP, and what opportunities there are for Support Group members to engage with work-related activity. Participants then had the opportunity to ask the DEA questions about this. After this, the DEA left and participants were asked for their views on what they had heard.

The research deliberately recruited people who had some interest in work, since people closer to work would be able to discuss the kinds of support that might help them.

Between four and eight participants took part in each group; 37 participants in total. Participants were welcome to bring carers and supporters (e.g. a friend or family member); and interpreters took part alongside the participants in the focus group with hearing impaired people.

Hastings and Leeds were chosen to complement the locations chosen for the in-depth interviews, and because there were significantly higher volumes of relevant claimants in these areas. These focus groups only included claimants in the ESA Support Group and did not include claimants in the UC-LCWRA group.

The sample for the Leeds and Hastings focus groups was drawn by the DWP with potential participants sent advance letters explaining the purpose of the study and enabling them to opt out – ten per cent of individuals opted out of the research. Most didn't give a reason for opting out, although a small number (26 individuals) opted out because they felt their health condition would prevent them from participating.

Recruitment was monitored to get a broad mix of people by the following characteristics: distance from the labour market; age and gender; primary health conditions; and whether individuals had ever been in the WRAG (Work Related Activity Group).

Focus groups were structured according to the criteria set out in Table A2. This included one focus group that was specifically conducted to include people with hearing impairments, since only one hearing-impaired person had taken part in the in-depth interviews. It was also felt that they might have slightly different support needs that they would wish to discuss; and conducting the group separately meant it was possible to accommodate BSL interpreters and give each individual plenty of time to contribute. Individuals were identified and invited to take part via a support organisation in Gloucester. Six individuals took part, all of whom were Registered Deaf; one with partial hearing and the others with no hearing. All were users of British Sign Language (BSL); with varying levels of lip-reading ability.

Group	Definition
Leeds 1	Age 25+, stable or improving health conditions, unsure but might be able to work if right support in place
Leeds 2	Age 18-24, mixed conditions and attitudes to work
Leeds 3	Age 25+, fluctuating conditions, definite interest in work
Hastings 4	Age 25+, stable or improving conditions, definite interest in work
Hastings 5	Age 25+, fluctuating conditions, unsure but might be able to work if right support in place
Gloucester 6	Hearing impaired

Table A2: Focus group prof

Participants in Leeds group 1 were aged between 25 and 54 years. All participants had a physical health condition and some also had depression. Most said they had at least three conditions and had not worked in the last five years.

Nearly all participants in Leeds group 2 had a mental health condition, with most citing anxiety as their main condition. Some also reported having a physical condition such as a skin condition, or heart or mobility problems. The group was split between those that had and had not worked in the last five years.

Leeds group 3 were predominantly under 35 years and were more mixed in their characteristics. Most had multiple conditions, most commonly including at least one mental health condition. They were split between those who had and had not worked in the last five years. Mental health conditions included depression and anxiety most commonly, as well as paranoia and problems with anger.

Hastings group 4 were older than the other focus groups, covering age bands from 35 to 64 years but with the majority aged between 55-64 years. All participants reported having a physical health condition. Most had more than one condition, most of which were physical (a minority reported having depression). The group was divided between those who had worked in the last five years and had last worked longer than 5 years ago.

Hastings group 5 was mostly made up of participants between 25 and 34 years old, all of whom reported having depression or anxiety alongside another condition including learning difficulties, asthma, fibromyalgia, digestive problems and autism. They were evenly split between those who had worked in the last 5 years and those that had worked over 5 years ago.

Gloucester group 6 consisted of six participants with hearing impairments. All were Registered Deaf; one with partial hearing and the others with no hearing. All were

users of British Sign Language (BSL) with varying levels of lip-reading ability. Nearly all had another health condition beyond their hearing impairment, most commonly musculoskeletal conditions. Many had experience of working in the past.

Peer interviews

A total of four peer-to-peer interviews were completed, by two individuals in the ESA Support Group. Interviewers and respondents were recruited through a local council and via a charity devoted to helping individuals with health conditions who are looking to enter voluntary or paid work.

IFF Research held a day long training session in the local area, with the interviewers in advance of the interviewing itself. This covered both interviewing technique and more practical or logistical considerations, such as the process of arranging interviews and the importance of informed consent.

The aim of peer-to-peer interviewing is to access new perspectives on the subject from interviewers who are part of the respondent group, and who can therefore potentially:

- Interpret responses differently to professional researchers;
- Encourage respondents to be more open and honest in their responses than they might be with a professional researcher.

A further aim is to enable the respondent group to participate in the research process and co-create the findings.

While the findings of the peer interviews did enrich the study, the process of recruiting, facilitating and conducting the peer interviews posed several challenges:

- It was particularly difficult to recruit interviewers and interviewees from a group which is defined by their ESA Support Group/UC LCWRA benefit status. Firstly, intermediary organisations often did not know what benefits their clients received, and this in turn limited their ability to proactively identify those with the aptitude to be an interviewer. Secondly, it prevented interviewers from identifying others from their social network to take part as interviewees, because they did not know who receives what benefits (with the information about whether an individual is in the Support Group/LCWRA being particularly obscure).
- Despite reassurances, many individuals were reluctant to participate as either interviewers or interviewees, due to concerns that their benefits would be affected, and/or due to distrust of the DWP.
- These recruitment challenges in turn meant that the majority of interviewers did not know their interviewees. This had several implications. It meant that, in most cases, the intended pre-existing familiarity between the interviewer and interviewee was lost. It also meant it was essential that interviews took place in a controlled environment to safeguard the participants and offer additional support. This entailed using a more formal venue that did not help interviewers and interviewees to feel relaxed.
- Individuals' health conditions and disabilities impacted on how the interviews were conducted. With some planning, practical needs could be met (for instance, booking specific rooms for participants with physical disabilities or ensuring a

support worker was available for an interviewee with learning difficulties). Some of the interviewers felt that having support workers present might have helped, when they were feeling anxious about conducting the interviews.

Quantitative interviews

A total of 2,012 quantitative interviews were conducted with individuals in the ESA Support Group and UC equivalent; 1,945 over the phone and 67 online.⁶⁰

A stratified random sampling approach was adopted: younger claimants aged 18-24 and those claiming Universal Credit were less prevalent in the claimant population and so were oversampled to make it possible to achieve sufficient interviews to support separate analysis of findings for these two sub-groups.

A sample of 8,000 individuals was drawn by the DWP. The fieldwork outcomes for these 8,000 are outlined in Table A3 below.

Advance letters were sent out these 8,000 claimants, of whom 12 per cent responded to opt out of the research (approximately 78 per cent via telephone and 22 per cent via email). Many did not give a reason for opting out, those who did often reflected the reasons given in response to the qualitative research, i.e. that their health condition(s) would prevent them from participating.

The questionnaire design was informed by the findings of the qualitative research. The questionnaire design and 'flow' was further refined using feedback from a fiveday pilot exercise, involving a total of 30 telephone interviews.

Data were weighted in two stages, first to correct for non-response and second to correct for the oversampling (and thereby match the profile of the claimants as outlined in the DWP administrative data). The weights applied were as follows:

- Firstly, a non-response weight was applied by age, as this was the biggest proportional difference between the profile of the claimants in the DWP administrative data and the profile of the completed interviews.
- Secondly, design weights were to correct for our oversampling of Universal Credit claimants and those aged 18-24 (the drawn sample had been designed to over-represent Universal Credit and 18-24 year-olds, as otherwise the base for these categories would have been too low to permit subgroup analysis).
- Because of this weighting, and the stratified random sampling approach, we
 report on the survey findings as being 'claimants' rather 'respondents'. In terms
 of statistical confidence in the findings, the confidence interval is 2.17. This
 means we can be 95% confident that the true figure lies within + or 2.17
 percentage points of the survey finding.

⁶⁰ The online survey was developed to help make the survey more accessible and to cater for individuals who would not feel comfortable speaking about their condition and experiences over the phone.

Table A3: Sample outcomes

	Number	Population in scope of study (%)	Population in scope of fieldwork (%)
Number sampled	8,000		
Ineligible (not population of interest)	144		
In scope of study:	7,856	100%	
Cases not issued to interviewers (opt- outs)	930		
Invalid cases			
Fax/unobtainable/business number	1,141		
Total invalid cases:	1,141		
In scope of fieldwork:	5,785	74%	100%
Non-contact after agreed no. of call- backs	2,152	46%	
Refusals			
Refused: No/"other" reason given	1,242		
Refused: Cannot take part due to health	224		
Refused: Not available during fieldwork	118		
Refused: Concerns with data-linking	23		
Refused: Has a terminal illness	14		
Total refusals:	1,621	26%	35%
Completed interviews/Response rate	2,012	26%	35%

This shows that from a starting sample of 8,000, the response rate for those in scope of the study (calculated as "completed interviews/number of cases sampled minus number of ineligible cases") was 26 per cent; and the response rate for those in scope of fieldwork (calculate as "completed interviews/number of cases sampled minus number of ineligible cases, invalid cases, and cases not issued to interviews") was 35 per cent. Looking at a more detailed breakdown:

- 15 per cent of the records in scope of the study were unusable, due to the phone number not being accessible (e.g. it was a dead line, or a business number);
- Around one-third (28 per cent) of those in scope of fieldwork refused to participate when contacted and a further 19 per cent opted out in advance;
- Around two-fifths (37 per cent) of those in scope of fieldwork did not respond after an average of 10 attempts; and
- Around one-quarter (26 per cent) of those in scope of the study completed. With invalid and ineligible cases removed (i.e. those in scope of fieldwork), this rises to 35 per cent.

Eight per cent of the sample interviewed had a terminal illness, although this figure is likely to be higher among the real population of ESA SG and UC LCWRA claimants,

as those whom DWP's records indicated had a terminal illness were removed from the starting sample at the outset. The eight per cent therefore were claimants who were not recorded by DWP as having a terminal illness but who told us during the survey that they did. These claimants were then given the option of withdrawing from the survey or completing it, albeit with the option of skipping some of the less relevant questions.

Safeguarding

Across all interviews IFF adhered to an agreed safeguarding policy with DWP, whereby claimants were signposted to national support organisations where deemed necessary.

Condition	Claimants (n)	Claimants (%) (weighted)
Mental Health	· · · · · ·	
Depression	737	37%
Stress or anxiety	556	28%
Psychotic disorder or Schizophrenia	211	11%
Bipolar disorder	94	5%
PTSD, Post-Traumatic Stress Disorder	70	3%
Agoraphobia	50	3%
OCD/ Obsessive Compulsive Disorder	33	2%
Borderline personality disorder/Emotionally Unstable Personality Disorder	30	2%
Other mental health condition	123	6%
Musculoskeletal conditions		
Problems with your legs or feet	570	28%
Problems with your neck, shoulders or back	530	26%
Pain or discomfort	353	18%
Problems with your arms or hands	329	16%
Arthritis, Osteoarthritis	283	14%
Cerebral Palsy	42	2%
Osteoporosis	28	1%
Other condition related to bone or muscle problems or physical injury	144	7%
Other long-term conditions affecting major orga	ns or the whole	body
Problems with your bowel, stomach, liver, kidneys or digestion including Crohn's disease	400	20%
Heart problems or blood pressure including angina	391	20%
Chest or breathing problems including asthma	338	17%
Fibromyalgia	127	6%
Cancer	118	6%
COPD/Emphysema	113	6%
Skin conditions or allergies	106	5%
Brain Injuries/Conditions (Brain Damage, Brain Injuries, Brain Tumour Etc.)	75	4%
Incontinence/Bladder problems	63	3%
Thyroid Problems	52	3%
MS/Multiple Sclerosis	46	2%
Sleep Apnoea	30	2%
Other long-term condition	259	13%

Condition	Claimants (n)	Claimants (%) (weighted)
Other health problems/disabilities		
Fatigue or problems with concentration or memory	269	13%
Diabetes	250	12%
Learning disabilities	209	10%
Asperger's syndrome or autism	172	9%
Dizziness or balance problems	163	8%
Learning difficulties including dyslexia	148	7%
Difficulty in seeing (while wearing glasses or contact lenses)	147	7%
Epilepsy	143	7%
Difficulty in hearing	110	5%
Speech problems	88	4%
Progressive illness not covered above	85	4%
Stroke	62	3%
Migraine	43	2%
Myalgic Encephalomyelitis (ME)/Chronic fatigue syndrome (CFS)	41	2%
Downs Syndrome	39	2%
Sleep-Related Conditions (E.G. Insomnia, Sleep Disorder, Sleep Walking)	34	2%
Problems due to drug or alcohol addiction	27	1%
ADHD	23	1%
Other health problem or disability	134	7%

Base – all who agreed to disclose their condition: (2,002)

Deriving the closeness to paid/voluntary work variables

The question used to derive this variable can be found in Annex D: Survey Questionnaire.

Closeness to paid work

The survey asked all claimants who were not terminally ill or currently in work, several questions about their feelings about work and whether they felt they might be able to work in future, which were used to group claimants into three categories describing their closeness to work. The first question (E1), asked claimants which of the following statements was closest to how they currently felt about work: 'My health condition/ disability rules out work now and in the future'; 'I am currently unable to work but might be able to in the future if my health improves'; 'I could return to work now if the right job was available or I had the right support'. The second (E2) asked claimants who felt they would be able to work again, to what extent they would like to undertake paid work, and a follow up (E4) asks at what stage in the future they felt they would be able to undertake paid work. The categories that claimants were grouped into were:

- 'Health rules out work': Claimants who said that their health condition or disability ruled out work as an option now and in the future at the first question (E1). These people were not asked either of the follow up questions E2 or E4.
- 'Unlikely' to work: Claimants who either said that they would not like to work at all in the future (E2), or that they would never be able to return to work in the future (E4).
- 'Could' work: Claimants who said that they could work again either within the next year, in the next two years or later than two years (E4).

Closeness to voluntary work

The closeness to voluntary work categories were calculated in a similar way to closeness to work. Survey claimants were asked three questions: If they are currently doing or have ever done voluntary work (D5), to what extent they would be interested doing voluntary work in the future if they are not already (E5) and, if they expressed any interest, at what stage in the future they might be able to volunteer (E7). Claimants were then grouped into the following categories:

- 'Already doing': Claimants who said they are currently volunteering (D5).
- 'Could' volunteer: This includes all claimants who expressed any interest in voluntary work (E5), and is split into '1 year', '2 years' and '2+ years' depending on when they felt they would be able to volunteer in the future (E7).
- 'Unlikely': Claimants who either said they were not at all interested (E5), or who were interested but said they would never be able to volunteer in the future (E7).

The segmentation approach used

A more advanced form of analysis, known as segmentation, was used to examine A) responses to a selection of questions 'at once' and B) group respondents together according to similarities in said responses. The questions that were included in the segmentation were those that provided an indication of claimants' closeness to paid work (i.e. their attitudes towards and their feelings about entering paid work in the future), the perceived barriers that they face in entering paid work and the various

forms of support that they said they might be interested in to help them move closer to paid work. The segmentation was conducted using Latent Class Analysis.

Latent Class Analysis is a family of techniques based around clustering and data reduction. There are several main benefits of Latent Class Models:

- More varied types of question/variable scales can be used in the segmentation (scale types include nominal, categorical, ordinal, interval or counts);
- Rather than allocating each respondent to one cluster, the Latent Class Clustering approach assesses the probability that every case (user) belongs to every cluster. For a segmentation model which works well, these probabilities are usually close to 100% for the cluster a particular respondent is most associated with and 0% for the other clusters. This gives much more accurate cluster averages when analysing subgroups than with other methods;
- Its ability to apply Continuous Factors, a more sophisticated way of handling relationships between question responses. This addresses the common concern about traditional segmentations; namely that they tend to focus on the obvious relationships, masking more subtle relationships between other variables. By capturing any more obvious relationships separately in a 'Continuous Factor', the segmentation is then more able to detect more subtle relationships between the remaining variables.

Four groups of claimants were excluded from the segmentation analysis. These groups were:

- Claimants who reported that their health condition rules out paid work, and who therefore could not be asked questions about barriers and support options: 1,134 individuals;
- Claimants who reported that their condition was terminal, who again could not be asked questions about barriers and support options: 176 individuals;
- Claimants who reported that they were already in work: 42 individuals;
- Claimants who did not give a sufficient level of response to the barriers and support questions, in that they repeatedly selected a non-response option, such as "neither agree nor disagree", "don't know" or "refused": 22 individuals.

Annex B: In-depth Interviews Topic Guide

The following topic guide was used for the in-depth interviews:

ESA Support Group Research Topic guide (60-90 mins) J5823 Face to face

Interviews expected to be mostly 60-75 minutes, though some may be longer (up to 90 minutes)

A Interviewer instructions:

BEFORE THE INTERVIEW:

Check details of participant's disability/health condition; and benefit(s) they
receive, in advance (see details collected at recruitment) and tailor your
questions accordingly. Please also ensure you have checked details of any
adjustments needed to make the interview accessible; and have checked that
any specific arrangements are in place.

B Introductions (5 mins)

- *Interviewer introduces themselves* working for IFF Research, an independent research company.
- We've been commissioned by the Department for Work and Pensions to learn more about the lives of people receiving Employment Support Allowance/ Universal Credit when they are not able to work because of a health condition or disability. The research is to help Government to develop their services to people who receive Employment Support Allowance/Universal Credit by improving their understanding of their customers.
- Everything you say is anonymous the DWP won't know the names of who we spoke to; your views will be included in a report with the views of lots of other people in similar situations. Taking part won't have any effect on the benefits you receive or your relationship with the DWP, and the information will not be used during any Work Capability Assessments you may have in the future.
- For the research to be valuable, it would really help me if you can be as frank as possible – but if there is anything you'd prefer not to answer, just let me know.
 Similarly, if you want to take time out at any point, or stop altogether, just let me know.
- Check whether ok to record interview, with their permission for use by the IFF research team only.

C Participants' everyday lives, priorities, challenges (10 mins)

Thank you, that's great. How are you today? And how has your week been so far?

One of the main things I'm interested in is to understand a bit about what your life is like at the moment.

- Can you tell me a bit about your living situation?
 - PROBE: Who do you live with, if anyone? What's your relationship with them?
 - PROBE: And how do you feel about where you live?

And can you talk me through what a typical week is like for you? Imagine you're creating a mini picture of your normal life, for someone who knows nothing about it.

IF PARTICIPANT STRUGGLES OR FEELS THERE IS NO SUCH THING AS A TYPICAL WEEK, EXPLORE THE MOST RECENT 'NORMAL' WEEK (EXCLUDING ANY WEEKS THAT WERE OUT OF THE ORDINARY FOR SOME REASON).

- What sorts of things do you do? Do you have any routines, or regular activities?
 - IF SO: What sorts of things? What else?
 - PROBE FOR ANY WORK OR VOLUNTEERING
- Who do you see most often? PROBE: Are these friends, neighbours, people who support you? What sorts of situations do you see these people in? What do you do with them?
- What do you enjoy most, in your everyday life?
- What, if anything, frustrates or worries you?
- How content are you with your life at the moment? Why do you say that?
- Do you have any aspirations or things you'd like to achieve? IF SO: Can you tell me more?

D Reflections on disability/health condition(s), and key events relating to these (15-20 mins)

NB – WE WILL HAVE ASKED WHAT THEIR DISABILITIES/HEALTH CONDITION(S) ARE IN THE SCREENER SO WE DO NOT NEED TO ASK ABOUT THEM DURING THE INTERVIEW ITSELF

I gather you have been receiving Employment and Support Allowance/Universal Credit in relation to a health condition or disability. How does your condition or disability affect your everyday life?

- PROBE: Does this vary at all, from day to day, week to week, year to year? IF SO: In what ways? PROBE: How does this affect what you are able to do?NOTE KEY CHALLENGES, TO REVISIT LATER
- IF HAS MORE THAN ONE CONDITION: And how does having multiple health conditions affect your everyday life? PROBE: Do they interact at all? IF SO: How does this affect you?
- I'd like to understand a bit about how your disability or condition and its effects on your everyday life has maybe changed/evolved over the years. It might help if we plot this on a timeline.

INTERVIEWER TO TAKE OUT TIMELINE ON PAPER, AND INDICATE ARROW LEADING UP TO THE PRESENT DAY. So if this is where we are now, can you tell me about any key points when your health condition or disability, and its effect on your life, changed in any way? FOR EACH POINT DISCUSSED: What happened at this point? Roughly when was this? What difference did this make to your everyday life? IF THERE ARE NO NOTABLE EVENTS, BUT INSTEAD A GRADUAL CHANGE, EXPLORE WHAT HAS CHANGED AND OVER WHAT PERIOD.

[INTERVIEWER NOTE: Please go back as far as possible, but do not spend more than 5 minutes on this topic]

And looking back over this period, what sorts of support have you received <u>with your</u> <u>disability or health condition</u>? READ OUT: This could be from professionals, support organisations or community groups, family or friends.

• FOR EACH: Who was this from? What was it they helped with, and in what way(s)? What difference did this make, if any?

Looking back on all of this...

- Which types of support made the most positive difference to you? FOR EACH: Why?
 - Was there any organisation or services you particularly connected with or trusted? Who? Why? INTERVIEWER TO NOTE THESE INDIVIDUALS ONTO A 'LIST OF TRUSTED PARTIES' FOR REFERENCE LATER

How do you expect your disability or health condition to change in the future?

• PROBE: Do you think it will get better, worse, stay the same or fluctuate?

If you could get anything you wanted, to support you <u>with your disability or health</u> <u>condition</u> now, what would you like? Why?

- PROMPT: This could be from a range of different people like professionals, support organisations or community groups?
- PROBE: How would this make a difference to your life?
- What difficulty/problem would this address?
- Ideally, who would provide this? Why?
- [IF MULTIPLE SUGGESTIONS MADE]: Which one of these types of support do you think would be most valuable to you? Why?

[IF NOT SOUGHT SUPPORT BEFORE BUT IDENTIFY SUPPORT WANTED NOW]: What, if anything, has prevented you from trying to access this support?

- PROBE for reasons why: e.g. didn't need it, not sure who to speak to, difficulties in accessing support?
- PROBE: Are you aware of any organisations or services that might do this? Which?

E Receipt of PIP/DLA (5 mins) (ask only to claimants of these benefits – see details from sample)

I understand that you also receive PIP (Personal Independence Payment)/DLA (Disability Living Allowance), is that correct?

[INTERVIEWER: If participant is not receiving this benefit move on to the next section]

[IF PIP]: Do you receive the daily living component, the mobility component or both? How much do you receive for each per week/month?

 [IF UNABLE/UNWILLING TO ANSWER HOW MUCH THEY RECEIVE, ASK FOR EACH COMPONENT]: Do you know if you are receiving the standard rate or the enhanced rate?

[INTERVIEWER NOTE: Daily living standard rate is £55.65 per week, and enhanced is £83.10 per week. For the mobility component, the standard rate is £22 and the enhanced rate is £58].

[IF DLA]: Do you receive the care component, the mobility component or both? How much do you receive for each per week/ month?

 [IF UNABLE/UNWILLING TO ANSWER HOW MUCH THEY RECEIVE, ASK FOR EACH COMPONENT]: Do you know if you are receiving the lowest, middle or highest rate?

[INTERVIEWER NOTE: Care component ranges from £22 per week (lowest) to £55.65 (middle) and £83.10 (highest). For the mobility component, the lower rate is £22 and the higher rate is £58 per week.].

[IF PIP/DLA]: What difference does your PIP/DLA payment make to you?

- PROBE: Does it help you manage your health condition/disability at all? IF SO: How?
- PROBE: Does it make a difference to your overall wellbeing and quality of life? IF SO: How?
- [IF IT JUST CONTRIBUTES TO THEIR OVERALL INCOME, PROBE]: Are there
 any things that help you with your health condition/disability that you regularly
 pay for?
 - IF YES: What? PROBE: What difference does your PIP/DLA payment make to your ability to afford this (if any)?

F Reflections on ability to work, attitudes to work and key events relating to this (10-15 mins)

My next set of questions are about work you might have done in the past and how you feel about the idea of working. By 'working' I mean the whole range of work that someone could do, like voluntary or part-time work, and not just full-time employment. The DWP are interested to hear what you, and people in your situation, think about work. This will help them understand how they might be able to better help people who are interested in doing some work (either paid or voluntary) in the future.

Previous work experience (10 minutes)

Just to check, have you worked in the past?

- IF SO: When did you last work?
- IF SO: What did you do? When was this? PROBE: Was this paid work, or voluntary? Were you working full-time or part-time? [INTERVIEWER TO REVISIT TIMELINE ON PAPER AND ADD DETAILS OF ROLE]
 - And why did you leave this job?
 - [IF LEFT FOR HEALTH REASONS]: How supportive, if at all, was your employer about your health condition/disability? Do you think your employer could have done anything to help you stay in work? IF SO: Can you give me some examples?
- [IF HAS WORKED]: And, going further back, have you done any other sorts of work in the past?
 - IF SO: What sorts of things and when, roughly?

And looking back, since you have been out of work, have you had any advice, support or conversations with anyone about returning to work? This could be from professionals, support organisations or community groups, family or friends.

- PROBE FOR EACH SOURCE OF SUPPORT: Who provided this support? What was discussed? How helpful did you find this?
- [IF UC SAMPLE AND NOT MENTIONED]: Was any of this from Jobcentre Plus?
- PROBE: Was any of the support about helping you manage your disability or condition in the context of possibly working at some point? IF SO: Which?
- [IF FOUND MULTIPLE SOURCES OF SUPPORT USEFUL]: Which of these made the most positive difference to you? FOR EACH: Why?
 - Was there anyone you particularly connected with or trusted? Who? Why? INTERVIEWER TO NOTE THESE INDIVIDUALS ONTO A 'LIST OF TRUSTED PARTIES' FOR REFERENCE LATER

Work aspirations (10 minutes)

How do you feel about the idea of working, as things stand? INTERVIEWER TO REMIND PARTICIPANT WE ARE ALSO TALKING ABOUT VOLUNTARY, PART-TIME OR SELF-EMPLOYMENT HERE.

If you were to do some sort of work, what sort of thing(s) could you imagine yourself doing? PROBE: What else?

- PROBE: Why do you say that?
 - PROBE AS NEEDED: Roughly how many hours a week would this be? In what sort(s) of roles? And in what kind of organisation? How would you feel about returning to your last job? Why?
 - How realistic does this kind of role feel to you? Why? When do you think it could potentially happen, in the next 6 months, the next year, next few years or further ahead? INTERVIEWER TO NOTE ANY POSITIVES/BENEFITS OR CHALLENGES/CONCERNS MENTIONED
- Sometimes people have mixed feelings about working, and how possible it might be. If we take this sheet of paper – INTERVIEWER TO INDICATE SHEET OF PAPER WITH TWO COLUMNS –
 - What things would you say would be the positives or benefits to you working? PROBE: What else?
 - And what types of things do you see as challenges or concerns about working? INTERVIEWER TO ALSO RECAP AND ADD TO THE TWO-COLUMN LIST, ANY POSITIVES/BENEFITS OR CHALLENGES/ CONCERNS RE: THEIR IMAGINED POSSIBLE ROLE, FROM A MOMENT AGO

That's great. Let's look at this list of positives and challenges'.

• Going with your 'gut feel', which are the biggest positives about working? And which are the biggest challenges or concerns? Why?

Steps towards work (5 minutes)

[IF PARTICIPANT HAS SOME INTEREST IN WORK]: And if you could get anything you wanted, any support or advice, to make the idea of working in some way feel more achievable, what would you ask for? Why?

- PROBE: What, if anything, would help deal with the biggest things in your 'challenges or concerns' column?
- PROBE: What, if anything, would help build on the biggest things in your 'positives' column?

Who would be best placed to help you with these things?

- REFER BACK TO 'LIST OF TRUSTED PARTIES' could you imagine any of these people or organisations doing this? IF SO: Who would be most suitable? Why?
- *[IF NOT MENTIONED]*: How useful do you think Jobcentre Plus might be? Why?
- [IF CLAIMANT STRUGGLES HERE]: Would you be interested in help with finding voluntary work or work experience; applying for jobs or interview techniques; or confidence building?

- [IF YES]: What types of people or organisations would you like to get this help from?
- [IF YES]: How would you feel about talking to a specialist Disability Employment Advisor from Jobcentre Plus would be if they could offer this help? Why?

[IF PARTICIPANT HAS NO ASPIRATIONS/INTEREST IN WORK BUT MAY BE IN A POSITION TO WORK IN FUTURE]:

[INTERVIEWER NOTE: Skip this section if someone has a severe condition with no/ little prospect of improvement]

[IF DON'T FEEL WELL ENOUGH]: I understand that your health is a consideration at the moment. Is there anything that you think could help work become a possibility in the future?

[IF MENTIONED SUPPORT FOR HEALTH IN SECTION D]: Earlier you mentioned that you thought [X] might help support you with your disability or health condition. What impact, if any, do you think this might have on how achievable working is? Why?

G Final reflections and close (3 mins)

Thank you so much for your time today.

- Thinking about what we've been discussing, if you could make DWP <u>really</u> understand one thing about your experiences, what would it be? Why?
- Do you have any questions for me?

Finally, would you be willing to re-contacted about any other research we are doing with ESA/UC claimants as part of this study? For example, in the next few months we may be running some focus groups about how the DWP might be able to better help people who are interested in working find employment. *[IF YES: CONFIRM BEST CONTACT DETAILS TO REACH THEM AND NOTE BELOW].*

We are also looking for people to help us carry out interviews like these with other people they know. This would involve doing a few interviews with any friends you have who are claiming ESA but aren't currently being supported to find work. Is this something you might be interested in?

[IF YES: EXPLAIN WE WILL MAKE A NOTE OF THEIR CONTACT DETAILS AND **MAY** BE IN CONTACT AT THE END OF THE YEAR TO DISCUSS THIS IN MORE DETAILS].

	Y	N	Contact details
Agreed to be re-contacted about other research			Name:
Agreed to be re-contacted about peer interviewing			Tel:
			Any other info / requests – best time to contact etc.

On behalf of IFF Research, the Department for Work and Pensions, thank you ever so much for your time and your input into this important research today.

[INTERVIEWER: Confirm address to send out £25 incentive too. If different to address of interview record below]

Address details		

I declare that this interview has been carried out under IFF instructions and within the rules of the MRS Code of Conduct.						
Interviewer signature:	Date:					
Finish time:	Interview Length	Mins				

Annex C: Focus Group Topic Guides

C1: The following topic guide was used for the Leeds and Hastings focus groups

ESA Support Group Research Topic guide (3 hours) Focus groups

J5823 Face to face, focus groups

A Introductions (10-15 mins)

BEFORE THE GROUP: Research team to check details of any adjustments needed to make the discussion accessible; and have checked that any specific arrangements are in place.

Moderator introduction (2-3 mins)

- Thanks very much for coming, I work for IFF Research, which is independent.
- The Department for Work and Pensions (DWP), has asked us to find out your views on help and support that might be offered to people to help them move towards work. To do this, we are going to talk about what you might want to do in future, and how you feel about the idea of working and activities to do with working. We are also going to discuss what help and support you've received in the past and what support you might want in future.
- We are giving you a gift of £50 in high street shopping vouchers as a thank you for giving up your time. This gift will not affect your benefit entitlements.
- Participation in this research is entirely voluntary and will not affect any benefits or tax credits you are claiming, now or in the future. Any information you provide will be held in the strictest of confidence and will be handled securely throughout the study. The research findings will not identify you and no personal information will be shared with anyone outside the research team.
- The discussion is being audio recorded so we can listen back when we are writing up the findings. Only the research team at IFF Research will have access to the recording. It will not be shared with anyone else, and it will be destroyed at the end of the project.
- IF RELEVANT: There are some researchers from the DWP observing at the discussion today, just so they can hear about people's views and experiences first-hand.
- Everything you say in the discussion will be in confidence; no attempt will be made to identify you; and as I said this will not affect any benefit or tax credit claims or your relationship with Jobcentre Plus or the DWP.

- The discussion will last for up to 3 hours, so we will build in a few breaks. Also, if you want to get up and move around, have a quick breather, grab a drink or go to the toilet at any point, please do!
- What you say today is very valuable to us, and we hope you will be happy to share your views and feelings. But if there is anything you don't wish to answer, or if you want to drop out altogether at any point – please just let me know – that is perfectly OK.

Hopefully this was all explained in the consent sheet we gave you to look at when you arrived. Are you happy to take part on this basis?

Participant introductions and warm up (10 mins)

Participants pair up and are given 5 minutes to find out each other's:

- First name and age;
- Something positive they would like to do in future; and
- What they think is the most common misconception about people receiving Employment and Support Allowance (misconception = thing people believe that is not true, if word is problematic for anyone.)

After 5 minutes, moderator invites participants to feed back by introducing the person next to them.

B Future aspirations, including around workrelated activity (15 mins)

I'd like us to start by thinking into the future. I want you to think ahead to a point where your life has maybe changed for the better – maybe a year, two or three years, five years or ten years, it's up to you, and you have a situation you are really happy with. You are working, or you've moved towards working, as much as you'd like to, with the right support in place to help you do that.

By 'work', I mean voluntary or paid work, full or part time, maybe bits of work on a freelance basis, or self-employment – the whole range of things that are to do with working, or getting closer to being able to work in some way.

What would this be like? PROBE: What sort of work would you be doing? Full or part time? Paid or voluntary? Self-employment? And what kind of support would you like to have to help you achieve this?

Moderator to hand out **individual A3 timelines, marked with years ('1 year from now', '2 years from now' etc., up to '10 years from now')**, and brief participants to write ideas about this future situation on a **yellow** post-it and place it on the timeline at **the relevant point in the future**. If any participants are visually impaired or have difficulty writing, moderator to take their input verbally and add their ideas in.

- PROBE:
 - And in this future situation, has anything improved to do with your health? IF SO: What? *Prompt participants to add to their timeline on another yellow post-it*
 - And in this future situation, has anything improved to do with your living arrangements or family, or other things you want to change in your life?
 IF SO: What? *Prompt participants to add to their timeline on another yellow post-it*
 - What steps would you need to take along the way? *Prompt participants to add to their timeline on another yellow post-it*
 - In roughly what order would these things need to happen? *Prompt participants to re-order items on their timeline.* PROMPT IF NEEDED: Would any of these things need to happen before you could take steps towards work, or could they happen after you start work?
- Moderator to review ideas on each timeline, probe around any that need clarifying, and note common themes to the group

C Support needs, to make work-related activity possible (35 mins, including break)

Now, I'd like us to think about the changes to your life that you've added to your timeline. What support might you need, to help these things to happen?

Moderator to brief participants to write ideas on **pink** post-its and add them to the timeline. If things happen in a particular sequence, participants to be encouraged to add them in that order. If any participants are visually impaired or have difficulty writing, moderator to take their input verbally and add their ideas in.

Moderator to review support ideas, probe around any that need clarifying – especially exploring why intermediate steps or types of support would lead to their desired outcomes. Moderator to note common themes to the group.

So, we're going to move on in a moment to talk about **who** you might want to provide this support. To get us thinking about this, I'd like us to think about situations where you have had a really positive experience of getting some kind of support previously – perhaps a situation where someone really helped change things for the better for you.

- What sort of support was this? PROBE: Who was it from? Where and when?
- What was the relationship like with the person or people who supported you? PROBE: What words or phrases would you need to describe it?
- And what made it good? PROBE: What else? Why?

So, that was a bit of a warm up. Who would you want to provide the kinds of support you just suggested you would like?

Moderator to revisit specific types of support suggested earlier and to probe – FOR EACH KEY SUPPORT NEED:

- Who would you want to deliver it and why?
- Where and when? Why?
- What would this relationship look like?
- What other 'do's and 'don't's can you suggest?

So thinking about these sorts of support you'd ideally like, to help you with your goals, what **stops you** getting this sort of support? *Probe around:*

- Lack of awareness of where to go;
- Perceived lack of availability;
- Support being available but not in the preferred manner/setting or at convenient times;
- Difficulty travelling there;
- Difficulty making time (explore reasons for this, if it applies).

And aside from practical difficulties, do you have any **concerns** about taking up this sort of support? IF SO: What? PROBE: What else? *Probe around:*

 Concern about situation/needs not being understood (explore specific nature of these concerns, if this applies – what do they feel will be misunderstood, and by whom – listen carefully for mentions of JCP or DWP);

 Concern about affecting benefit entitlements (explore specific nature of these concerns, if this applies – and which benefits they mean – listen carefully for mentions of PIP/DLA and ESA/UC).

Do any of these concerns or difficulties apply **more** to certain types of support? *Explore, prompting with their specific 'wish-list' of support from timeline.*

- IF MULTIPLE CONCERNS/BARRIERS: Which of these concerns or difficulties are most daunting for you? Why?
- TAKE AS MANY OF THESE CONCERNS/BARRIERS AS POSSIBLE, STARTING WITH THE 'MOST DAUNTING': What would need to happen to help you get past this difficulty/concern? Who could you imagine helping you with this? Why?
- We're going to move on again in a moment, but first of all we'll take a quick 5-minute break.

Group reconvenes.

D Perceptions of DWP and JCP (20 mins)

IF RELEVANT: We've talked a bit about this already, but now we're going to talk about in more detail.

- What words or phrases spring to mind when I say '**the Department for Work** and Pensions/the DWP'? Why? Where does this idea of them come from? And how would you describe your relationship with them? (Is there one?) Why?
- And what words or phrases spring to mind when I say 'Jobcentre Plus'? Why?Where does this come from? And how would you describe your relationship with them? (Is there one?) Why?

Just to check, are we lumping the DWP and Jobcentre Plus together here, or do you see them as different? Why? IF DIFFERENT: In what way, different?

Let's think about the goals to do with working, or easing your way back towards work, that you suggested earlier – you said things like [X, Y and Z – recap]. To make progress towards these, you said you wanted support with [A, B and C – recap]. Can you imagine the **DWP or Jobcentre Plus playing a role** in providing any of this support?

- PROBE: Which things do you really believe they could help you with? PROBE: Would you trust them to do this? Why?
- PROBE: And are there any of these things that you **can't** imagine them helping with? PROBE: Any that you would **not** trust them to help with? IF SO: Which ones? Why?

Just to check, would it be Jobcentre Plus or the DWP who you think could help you more with this, or doesn't it matter? Why?

Unpick throughout the above whether it is DWP or JCP they are talking about: if it is apparent that either the DWP or JCP figures much more in their thinking, explore whether the other one could play a role (if it is seen as more of a 'neutral' agency).

IF NOT EMERGED SPONTANEOUSLY: What sort of dealings have you had with the DWP or Jobcentre Plus in the past? *Probe for whether referencing DWP or JCP or both.*

- PROBE: Have you received any support to help you move closer to work from them? IF SO: What was this? *Prompt with Access to Work, Permitted Work, Work Choice.*
 - IF RECEIVED SUPPORT: How did you feel about this support? Why? PROBE: What was positive about this (if anything)? And what could have been better (if anything)?
 - IF ANY SUPPORT OR OTHER DEALINGS: Have any of your dealings with Jobcentre Plus been at their offices? How did you feel about being in the Jobcentre, as a place? Why? PROBE: What was it like? PROBE: What was positive about this (if anything)? And what was negative about it (if anything)?
 - How much does it feel like a suitable place to receive the sorts of support you said you wanted? Why? And what, if anything, could make it more suitable as a place for you to receive support?

IF BARRIERS TO THE DWP OR JCP PLAYING A ROLE IN SUPPORTING THEM (TAILOR SECTION ACCORDINGLY): You summed up your view of the DWP as being [X, Y and Z – recap] and your view of Jobcentre Plus being [X, Y and Z – recap]. How would they need to change, for them to play more of a role in helping you reach your goals to do with work?

• And how would you know that they had changed? PROBE: In your everyday encounters with them, what would the signs be?

E Testing relevance and appeal of support options – deliberative element (65 mins, including break)

DEA briefing, and Q&A (25 mins, including break)

We've just explored your current views on the DWP and Jobcentre Plus. The next thing we want to do is brief you on what Jobcentre Plus currently offers, in case any of this is new to you or changes your opinion in any way. You may have heard of all of this before, or it may be new; some of it might change your views or your views might stay the same – either is fine; we just want you to be frank!

JCP Disability Employment Advisor, to briefly talk to participants, using a script, about:

- What support Jobcentre Plus currently offers, including via partners;
- What the process, expectations and consequences would be, if they volunteered to receive some of this support.

**Key support concepts to be reinforced by simple concept wordings on cards.

DEA Information

Overview of support available through the JCP offer

- voluntary work/work experience what claimants are able to do within the benefit rules
- permitted work and what the rules are
- 12 week linking rule enabling people to return to the Support Group if work doesn't work out
- referrals to providers who have expertise in helping people with disabilities or health conditions move into work/closer to work, or into self-employment
- local support [please add in some examples of provision in your local area]
- training/skills opportunities
- Access to Work and reasonable adjustments
- Disability Confident employer scheme

Describing what the process would be if someone wanted to find out more and talk to their local jobcentre about support:

- how would they go about making contact
- would they have to go into their local jobcentre, can it be done by phone
- flexibility of appointment times
- availability of private interview rooms, disabled access
- ability to bring someone with them
- who would they speak to a work coach, DEA, how long would it last
- what would typically happen/be covered during the first conversation
- what would happen at the end of the conversation/what happens next
- what information would be recorded about them on the JCP system

Reassurances – claimants may have various concerns about how asking for support could affect their benefit claim status:

- that volunteering for support or undertaking voluntary work would not affect their benefit claim/their position in the Support Group
- volunteering for support would not trigger a WCA re-assessment
- engaging in support would remain voluntary and they could stop at any time without the risk of being sanctioned

Moderator to listen to spontaneous comments or questions during this talk. Relevant participant queries to be noted and briefly answered if possible. At end of this talk, time to be allowed for a brief Q&A session. Talk and Q&A to last 20 mins – 15 minute talk and ad hoc queries; 5 minute Q&A. Moderator notes any spontaneous comments from participants.

We're going to take a quick 5-minute break now while you have a think about what you've just heard, then we'll come back together to talk about what you thought of it.

Participant discussion of their views on DEA briefing (20 mins)

Group reconvenes. Then moderator to explore (20 mins):

- What do you think of what you just heard? Why?
- Are there any surprises? IF SO: What? PROBE: Is any of what would happen, if you volunteered to take up support, different to what you thought? IF SO: What? What did you *think* would happen?
- What parts of the support available seem relevant to you, and what you said you'd like to do? IF SO: What, and why? And were you aware the DWP/ Jobcentre Plus offered this? *If so, explore what they were aware of and what is 'new' to them.* **Prompt them to add to their timeline, in a relevant place (if they can).**
- And what types of support that you said you'd ideally want **don't** seem to be offered by Jobcentre Plus, based on what you just heard? PROBE: What else?
- What based on what you've just heard, how would you feel about taking up some of this support from Jobcentre Plus? PROBE: Any concerns, or anything that might get in the way of you doing this? *Moderator to note barriers*
 - REVISIT THESE BARRIERS, ONE BY ONE: What might help you get past these concerns, or things that are stopping you?

Discussion of specific support option/concept (15 mins)

I've now got an idea for ways in which support might be offered in future.

**Support concept to be shown and read, by the moderator, using simple concept wordings on cards.

Support from a case worker – Key Features

A dedicated case-worker who would provide 1-2-1 intensive support tailored to your individual needs. They would work with you to identify your support needs based on your circumstances, help to prioritise these and support you to access appropriate help.

This could be at a location of your choice – at home, a local community centre, café

Support Includes:

- Detailed assessment of needs, barriers and prioritisation of these
- Supporting you to contact other organisations or contacting them on your behalf e.g. housing, debt, counselling or health condition management programmes
- Travelling with you to appointments and/or attending appointments with you
- Accompanying you to activities e.g. training courses
- Identifying activities to help you move closer to work e.g. voluntary work and helping you to access suitable opportunities
- Helping you talk to organisations or employers about your health condition and how it may affect you
- In and out of work benefits advice and support
- In-work support

Moderator to listen to spontaneous comments or questions during this talk. Relevant participant queries to be noted and briefly answered if possible. Then moderator to explore:

- FOR EACH: What do you think of this? Why?
- REVIEWING ALL: Does any of this seem relevant to you, and what you said you'd like to do? IF SO: What, and why? *Prompt them to add to their timeline, in a relevant place (if they can).*

Leaving all cards on show – current support and new ideas – and re-capping all of these by reading them out once again.

- And how do you *really* feel about volunteering for any of this support? PROBE: Would you do it? Why/why not? *Explore any specific parts of the offer that are more compelling than others.*
- Do you still have any concerns? IF SO: What? IF CONCERNS: What would need to happen to reassure you about this? PROBE: Can you be reassured? Why/why not?

F Communicating and engaging participants re: this support (20 mins)

So we've talked about a number of things that Jobcentre Plus offers now, and some new ideas for what it could do. What's the best way of telling you about this? PROBE: Where and how would you learn about it?

 [IF RELEVANT: You said the most appealing aspects were [X, Y and Z – recap]]. What should they tell you about this, the first time they contact you, to get you interested?

If you received a letter or a phone call from your local Jobcentre Plus, inviting you to come in for a meeting with a work coach to discuss your circumstances and tell you about the support on offer, how would you feel about this? Why? *Listen for perception of being 'hassled', and explore reasons for this.*

- IF ANY NEGATIVE CONNOTATIONS WITH THE COMMUNICATION: How could they make this more positive?
- ALL: At what points could this feel more appropriate? Why?
- ALL: How often would this be appropriate e.g. every 6 months, every year, never? Why?
 - PROBE: What, if anything, would help Jobcentre Plus know that this would be a good time to contact you? How would you feel about contacting Jobcentre Plus to let them know?
- ALL: If they did contact you, what would you prefer a phone call, letter or email? Why? PROBE: And which would you be more likely to respond to? Why?
 - Probe for –interest in hard copy versus digital communication

Just to check, would this be better coming from the DWP, Jobcentre Plus, or another organisation? Who would you be OK about talking to? Why?

And are there any points in the past when you wish the DWP or Jobcentre Plus **had** got in touch to discuss your circumstances and tell you about the support on offer? PROBE: Any points when it might have felt appropriate or helpful to you? IF SO: When? Why?

- Probe for after they applied for ESA; after they heard the outcome of their Work Capability Assessment, and explore reasons for views.
- FOR ANY POINTS WHERE IT FEELS APPROPRIATE: What specifically might they have said to you at these points, to get your interest?

How do you feel generally about the fact that you don't normally have to have any dealings with the Jobcentre Plus or the DWP?

• PROBE: Positive, negative, or a bit of both? Why? Listen for 'it being a relief vs. 'feeling written off'.

G Final reflections and close (10 mins)

Thank you so much for your time today.

- Out of all the different types of support we have discussed today, what is the one thing that would make the biggest difference to you?
- [ASK IF TIME]: Overall, how likely do you think it is that you will have actively done something to move towards working in 6 months' time?
 - [IF 6 MONTHS TOO SOON]: What would be a more suitable timescale for you?
- Do you have any questions for me?

Finally, would you be willing to re-contacted about any other research we are doing with ESA claimants as part of this study? We are looking for people to help us carry out interviews like these with other people they know. This would involve doing a few interviews with any friends you have who are claiming ESA but aren't currently being supported to find work. Is this something you might be interested in?

[IF YES: EXPLAIN WE WILL MAKE A NOTE OF THEIR CONTACT DETAILS AND **MAY** BE IN CONTACT AT THE END OF THE YEAR TO DISCUSS THIS IN MORE DETAILS]. USE COPIES OF SHEET BELOW FOR THIS: OF SHEET BELOW FOR THIS:

	Y	N	Contact details
Agreed to be re-contacted about peer interviewing			Name:
			Tel:
			Any other info / requests – best time to contact etc.

On behalf of IFF Research, the Department for Work and Pensions, thank you ever so much for your time and your input into this important research today.

[INTERVIEWER: Confirm each participant has signed consent form, and received shopping vouchers and signed for these]

C2: The following topic guide was used for the hearing impaired focus group

ESA Support Group Research Topic guide (3 hours) Focus groups (hearing impaired)

J5823 Face to face, focus groups

A Introductions (15 mins)

BEFORE THE GROUP: Research team to check details of any adjustments needed to make the discussion accessible; and have checked that any specific arrangements are in place.

Moderator introduction (2-3 mins)

- Thanks very much for coming, I work for IFF Research, which is independent.
- The Department for Work and Pensions (DWP), has asked us to find out your views on help and support that might be offered to people to help them move towards work. To do this, we are going to talk about what you might want to do in future, and how you feel about the idea of working and activities to do with working. We are also going to discuss what help and support you've received in the past and what support you might want in future.
- We are giving you a gift of £50 in high street shopping vouchers as a thank you for giving up your time. This gift will not affect your benefit entitlements.
- Participation in this research is entirely voluntary and will not affect any benefits or tax credits you are claiming, now or in the future. Any information you provide will be held in the strictest of confidence and will be handled securely throughout the study. The research findings will not identify you and no personal information will be shared with anyone outside the research team.
- The discussion is being audio recorded so we can listen back when we are writing up the findings. Only the research team at IFF Research will have access to the recording. It will not be shared with anyone else, and it will be destroyed at the end of the project.
- Everything you say in the discussion will be in confidence; no attempt will be made to identify you; and as I said this will not affect any benefit or tax credit claims or your relationship with Jobcentre Plus or the DWP.
- The discussion will last for up to 3 hours, so we will build in a few breaks. Also, if you want to get up and move around, have a quick breather, grab a drink or go to the toilet at any point, please do!
- What you say today is very valuable to us, and we hope you will be happy to share your views and feelings. But if there is anything you don't wish to answer, or if you want to drop out altogether at any point – please just let me know – that is perfectly OK.

Hopefully this was all explained in the consent sheet we gave you to look at when you arrived.

Are you happy to take part on this basis?

Participant introductions and warm up (15 mins)

Participants pair up and are given 5 minutes to find out each other's:

- First name and age; and
- Something positive they would like to do in future

After 5 minutes, moderator invites participants to feed back by introducing the person next to them.

B Future aspirations, including around workrelated activity (30 mins)

I'd like us to start by thinking into the future. I want you to think ahead to a point where your life has maybe changed for the better – maybe a year, two or three years, five years or ten years, it's up to you, and you have a situation you are really happy with. You are working, or you've moved towards working, as much as you'd like to, with the right support in place to help you do that.

By 'work', I mean voluntary or paid work, full or part time, maybe bits of work on a freelance basis, or self-employment – the whole range of things that are to do with working, or getting closer to being able to work in some way.

Moderator to brief participants to write ideas about this future situation on a **yellow** post-it note. If any participants are visually impaired or have difficulty writing, moderator to take their input verbally and add their ideas in.

Moderator to discuss with the group: What would this be like? PROBE: What sort of work would you be doing? Full or part time? Paid or voluntary? Self-employment?

And what kind of support would you like to have to help you achieve this?

- PROBE:
 - And in this future situation, has anything improved to do with your health? IF SO: What?
 - And in this future situation, has anything improved to do with your living arrangements or family, or other things you want to change in your life? IF SO: What?
 - What steps would you need to take along the way?
 - In roughly what order would these things need to happen? PROMPT IF NEEDED: Would any of these things need to happen before you could take steps towards work, or could they happen after you start work?

C Support needs, to make work-related activity possible (45 mins, including break)

So, we're going to move on in a moment to talk about **what support you might need** to help these aspirations and hopes you have for the future to happen, and **who** you might want to provide this support. To get us thinking about this, I'd like us to think about situations where you have had a really positive experience of getting some kind of support previously. For example, I understand that all of you are taking part in the GEM project? Can you tell me a little bit about this?

- What sort of support are you getting through the GEM project? Are there any aspects of the GEM project which are particularly helpful? Why?
- Can you describe the relationship you have with the person who runs the activities you participate in? PROBE: What words or phrases would you need to describe this relationship?
- And what made it good? PROBE: What else? Why?
- Is there anything else you wish the GEM project could offer you or help you with?

So, that was a bit of a warm up.

What support might you need, to help these aspirations and hopes you have for the future to happen? PROBE: What else might you need?

Moderator to review support ideas, probe around any that need clarifying – especially exploring why intermediate steps or types of support would lead to their desired outcomes.

And thinking about these kinds of support...

(Moderator to revisit specific types of support suggested earlier and to probe – FOR EACH)

- Who would you want to deliver it and why?
- Where and when? Why?
- What would this relationship look like?
- What other 'do's and 'don't's can you suggest?
- IF SUGGESTED THE GEM PROJECT: Aside from GEM, are there any other organisations you could imagine offering this support?
- Is there anything a new support offer could learn from the GEM project?

Do you have any **concerns** about taking up this sort of support, or is there anything that stops you taking it up? IF SO: What? PROBE: What else? *Probe around:*

- Concern about situation/needs not being understood (explore specific nature of these concerns, if this applies – what do they feel will be misunderstood, and by whom – listen carefully for mentions of JCP or DWP);
- Concern about affecting benefit entitlements (explore specific nature of these concerns, if this applies – and which benefits they mean – listen carefully for mentions of PIP/DLA and ESA/UC).

We're going to move on again in a moment, but first of all we'll take a quick 5-minute break.

Group reconvenes.

D Testing relevance and appeal of support options – deliberative element (60 mins, including break)

JCP offer briefing, and Q&A (40 mins, including break)

We've just explored your current views on the DWP and Jobcentre Plus. The next thing we want to do is brief you on what Jobcentre Plus currently offers, in case any of this is new to you or changes your opinion in any way. You may have heard of all of this before, or it may be new; some of it might change your views or your views might stay the same – either is fine; we just want you to be frank!

**Key support concepts to be reinforced by simple concept wordings on cards.

So, what Jobcentre Plus currently offers...

- What's on offer has changed quite a lot. The DWP has dedicated Disability Employment Advisors who are training up the JCP work coaches to make them more skilled in working with people with disabilities and health conditions. They are also working more closely with outside organisations that work with people with disabilities and health conditions, to help them move closer to work and with employers, to encourage them to think about taking on people with disabilities and health conditions. They are trying to get support organisations and employers into the Jobcentre more to interact with JCP customers.
- If you are in the ESA Support Group and decided that you were interested in moving closer to work, you could get in touch with Jobcentre Plus. They could direct you to help from the Health & Work Programme, delivered by an organisation called pluss, who are offering intensive support to people with health conditions to help them to get into work, and to support them to stay in work
- JCP could help you source voluntary or work experience placements. This includes 'Move Into Work' which is where people can do work experience within Jobcentres
- JCP offer skills courses that are open to anyone such as basic IT courses, and job-specific skills such as care work these include both on the job and college-based training and result in a guaranteed interview at the end
- Access to Work this is run by the DWP and is funding for people with disabilities and health conditions who go into a job and need adjustments making – the funding is to help adjustments being made. This can include travel to work or things like sign language interpreters, ergonomic chairs; anything that can help someone move into work and stay in work
- Permitted work this is for people on ESA; you can work up to 16 hours and earn up to £120 per week without losing benefits to allow them to try work but with a 'safety net'

- The linking period allows you to stop claiming ESA while you start work, for up to 12 weeks, and then within this 12 weeks period you can to return to the Support Group without having to reapply if the work doesn't work out
- If you want to talk about this, there are private interview rooms available at Jobcentre Plus, and they can arrange appointments for times of the day when it's quieter or speak over the phone if you prefer
- The Disability Confident employer scheme is an accreditation that signals that an employer is committed to being inclusive, provides reasonable adjustments to employees and will guarantee an interview to disabled people.
- Just to reassure you, volunteering for support or undertaking voluntary work would not affect their benefit claim/their position in the Support Group, will not trigger a Work Capability Re-assessment; and engaging in support would remain voluntary and you could stop at any time without the risk of being sanctioned

Moderator to listen to spontaneous comments or questions during this talk. Relevant participant queries to be noted and briefly answered if possible. Moderator notes any spontaneous comments from participants.

Then moderator to explore (30 mins):

- What do you think of what you just heard? Why?
- Are there any surprises? IF SO: What? PROBE: Is any of what would happen, if you volunteered to take up support, different to what you thought? IF SO: What? What did you *think* would happen?
- What parts of the support available seem relevant to you, and what you said you'd like to do? IF SO: What, and why? And were you aware the DWP/ Jobcentre Plus offered this? *If so, explore what they were aware of and what is 'new' to them.* **Prompt them to add to their timeline, in a relevant place (if they can).**
- And what types of support that you said you'd ideally want **don't** seem to be offered by Jobcentre Plus, based on what you just heard? PROBE: What else?

Discussion of specific support option/concept (20 mins)

I've now got an idea for ways in which support might be offered in future.

**Support concept to be shown and read, by the moderator, using simple concept wordings on cards.

Support from a case worker – Key Features

A dedicated case-worker who would provide 1-2-1 intensive support tailored to your individual needs. They would work with you to identify your support needs based on your circumstances, help to prioritise these and support you to access appropriate help.

This could be at a location of your choice – at home, a local community centre, café

Support Includes:

- Detailed assessment of needs, barriers and prioritisation of these
- Supporting you to contact other organisations or contacting them on your behalf e.g. housing, debt, counselling or health condition management programmes
- Travelling with you to appointments and/or attending appointments with you
- Accompanying you to activities e.g. training courses
- Identifying activities to help you move closer to work e.g. voluntary work and helping you to access suitable opportunities
- Helping you talk to organisations or employers about your health condition and how it may affect you
- In and out of work benefits advice and support
- In-work support

Moderator to listen to spontaneous comments or questions during this talk. Relevant participant queries to be noted and briefly answered if possible. Then moderator to explore:

- What do you think of this? Why?
- Does any of this seem relevant to you, and what you said you'd like to do? IF SO: What, and why?

Leaving all cards on show – current support and new ideas – and re-capping all of these by reading them out once again.

- And how do you *really* feel about volunteering for any of this support? PROBE: Would you do it? Why/why not? *Explore any specific parts of the offer that are more compelling than others.*
- Do you still have any concerns? IF SO: What? IF CONCERNS: What would need to happen to reassure you about this? PROBE: Can you be reassured? Why/why not?
- What based on what you've just heard, how would you feel about taking up some of this support from Jobcentre Plus? PROBE: Any concerns, or anything that might get in the way of you doing this? *Moderator to note barriers*
 - REVISIT THESE BARRIERS, ONE BY ONE: What might help you get past these concerns, or things that are stopping you?

E Final reflections and close (15 mins)

Thank you so much for your time today.

- Out of all the different types of support we have discussed today, what is the one thing that would make the biggest difference to you?
- [ASK IF TIME]: Overall, how likely do you think it is that you will have actively done something to move towards working in 6 months' time?
 - [IF 6 MONTHS TOO SOON]: What would be a more suitable timescale for you?
- Do you have any questions for me?

Finally, would you be willing to re-contacted about any other research we are doing with ESA claimants as part of this study? We are looking for people to help us carry out interviews like these with other people they know. This would involve doing a few interviews with any friends you have who are claiming ESA but aren't currently being supported to find work. Is this something you might be interested in?

[IF YES: EXPLAIN WE WILL MAKE A NOTE OF THEIR CONTACT DETAILS AND **MAY** BE IN CONTACT AT THE END OF THE YEAR TO DISCUSS THIS IN MORE DETAILS]. USE COPIES OF SHEET BELOW FOR THIS:

	Y N	Contact details
Agreed to be re-contacted about peer interviewing		Name:
		Tel:
		Any other info / requests – best time to contact etc.

On behalf of IFF Research, the Department for Work and Pensions, thank you ever so much for your time and your input into this important research today.

[INTERVIEWER: Confirm each participant has signed consent form, and received shopping vouchers and signed for these]

Annex D: Survey Questionnaire

The following questionnaire was used for the quantitative survey:

ESA Support Group Research quant survey

J5823 Telephone

S Telephone screener

ASK PERSON WHO ANSWERS PHONE

S1 Good morning/afternoon/evening. My name is and I'm calling from IFF Research. Please can I speak to [CLAIMANT NAME]?

Respondent answers phone	1		
Transferred to respondent	2	CONTINUE	
Hard appointment	3	MAKE	
Soft Appointment	4	APPOINTMENT	
Engaged	5	CALL BACK	
Refusal	6		
Not available in deadline	7		
Fax Line	8	CLOSE	
No reply/Answer phone	9		
Business Number	10		
Dead line	11		
Request reassurance email	12	COLLECT EMAIL ADDRESS THEN CONTINUE OR MAKE APPOINTMENT	
		(SEE APPENDIX FOR EMAIL TEXT)	
Needs reassurances	13	GO TO REASSURANCES	

ASK ALL

S2 Good morning/afternoon, my name is NAME, calling from IFF Research, an independent market research company, on behalf of the Department for Work and Pensions.

We are carrying out this survey to understand people's experiences of claiming Employment Support Allowance or Universal credit because of a disability or health condition and their support needs. By taking part, you'll be adding your voice to hundreds of other people to help DWP develop their services. Your details were selected at random from DWP's claimant records.

We would really like to hear about your views and experiences, but taking part in this survey is completely voluntary and you can refuse to answer individual questions or withdraw at any time. The survey should take no longer than 30 minutes to complete.

The survey is being carried out by IFF Research, an independent research company. The research has been commissioned by the Department for Work and Pensions (DWP).

INTERVIEWER: EVEN IF RESPONDENT HAS ALREADY AGREED, YOU MUST BE SURE TO READ OUT:

Before we begin I just need to read out a few statements. Firstly, your answers may be linked to other information held by the Department for Work and Pensions so that they can analyse the results. However, the information you provide is treated in strict confidence and will not affect your dealings with the Department for Work and Pensions, nor any benefits you may be claiming. The research findings will be published online, but they will not identify you.

DWP collects and processes your survey responses to improve the services it provides as part of its public authority duty. The data from the survey will be held by DWP for 10 years. After this it will be securely destroyed.

If you would like further information about how DWP handles your information you can find this on the DWP's Personal Information Charter on gov.uk. You can also see more about your personal information rights on the Information Commissioner's Office website. Would you like any more details about these?

INTERVIEWER NOTE - LINKS ARE:

HTTPS://WWW.GOV.UK/GOVERNMENT/ORGANISATIONS/DEPARTMENT-FOR-WORK-PENSIONS/ABOUT/PERSONAL-INFORMATION-CHARTER AND HTTPS://ICO.ORG.UK.

Finally, all interviews are recorded automatically as part of our quality control procedures.

Based on this information, are you willing to take part?

INTERVIEWER NOTE: YOU MUST GET A CLEAR 'YES', OR SIMILAR RESPONSE, TO INDICATE CONSENT TO TAKING PART

Yes: Continue – happy to take part	1	CONTINUE
Referred to someone else in household NAME	2	TRANSFER AND RE-INTRODUCE
Hard appointment	3	MAKE APPOINTMENT
Soft appointment	4	
Refusal	5	
Cannot take part due to health condition	6	
Refusal – concerns with data linking	7	
Refusal – taken part in recent survey	8	
Refusal – Other reason		
<i>IF REASON GIVEN SPONTANEOUSLY, WRITE IN:</i> WRITE IN:	9	THANK AND CLOSE
Not available in deadline	10	
Foreign language request	11	RECORD PREFERRED LANGUAGE AND GO TO S2e
Request reassurance email	12	COLLECT EMAIL ADDRESS THEN CONTINUE OR MAKE APPOINTMENT (SEE APPENDIX
Needs reassurances	13	FOR EMAIL TEXT) GO TO REASSURANCES

IF REFUSED (S1=6 or S2=5,8,9,10).

S2a Would you be willing to take part online instead?

Yes	1	COLLECT EMAIL ADDRESS AND THANK AND CLOSE
No	2	THANK AND CLOSE

ASK IF CANNOT TAKE PART DUE TO HEALTH CONDITIONS (S2=6)

S2b Is there anything we could do to support you in taking part in this interview, which would make it possible for you to take part...?

PROMPT ONLY IF NECESSARY, STARTING WITH 'COMPLETE ONLINE', THEN 'PAPER QUESTIONNAIRE'. PLEASE ONLY OFFER FACE-TO-FACE IF THEY CANNOT TAKE PART BY ANY OTHER METHOD.MULTI-CODE.

ONLY READ OUT IF CANNOT TAKE PART BY ANY OTHER METHOD: A face-to-face interview	1	GO TO S2C
An online interview	2	COLLECT EMAIL ADDRESS AND THANK AND CLOSE
A paper questionnaire	3	GO TO S2D
Other (please specify)	4	GO TO S2C
No: there is nothing you can offer	5	THANK AND CLOSE
Don't know [DS – EXCLUSIVE CODE]	6	THANK AND CLOSE

ASK IF REQUEST F2F INTERVIEW OR SOMETHING ELSE (S2B=1 OR 4)

S2c [IF S2b=1: Thank you, a colleague will be in touch soon to arrange the best time and place for a face-to-face interview] [IF S2b=4: Thank you, I will be in touch again about this soon]. What would be the best number to reach you on?

WRITE IN NUMBER 1: WRITE IN NUMBER 2:

ASK IF REQUEST PAPER QUESTIONNAIRE UNDER S2b=3

S2d Thank you, what would be the best address to send this to?

INTERVIEWER NOTE: YOU DO NOT NEED TO COLLECT BOTH AN EMAIL AND A POSTAL ADDRESS, WHICHEVER THE RESPONDENT GIVES YOU IS FINE.

WRITE IN EMAIL ADDRESS:

WRITE IN POSTAL ADDRESS:

Don't know [DS – EXCLUSIVE CODE]	1	THANK AND CLOSE
Prefer not to say [DS – EXCLUSIVE CODE]	2	THANK AND CLOSE

ASK IF FOREIGN LANGUAGE REQUEST (S2=11)

S2e Please can you tell me your level of English?

Don't know [DS – EXCLUSIVE CODE]	1	THANK AND CLOSE
Prefer not to say [DS – EXCLUSIVE CODE]	2	THANK AND CLOSE

ASK ALL

S4 Before we start, please let us know who is answering this survey. Are you...?

READ OUT. SINGLECODE

The person receiving Employment and Support Allowance (ESA) or Universal Credit (UC)	1	
A formal appointee of the person receiving Employment and Support Allowance (ESA) or Universal Credit (UC)	2	
Not a formal appointee, but a carer, family member or friend of the person receiving Employment and Support Allowance (ESA) or Universal Credit (UC)	3	

ASK IF RESPONDENT SAYS THEY ARE A FORMAL APPOINTEE BUT NOT MARKED AS AN APPOINTEE ON SAMPLE (S4=2 AND SAMVARS 'APPOINTEE'=2)

S4a Thank you. Would you be ok with us notifying the DWP's research team that they have an appointee? This will just help the DWP improve their processes for future research.

Yes	1	
No	2	

ASK ALL

S3 Some of the questions in this survey may not be appropriate or relevant for people with a terminal illness. If this applies to [S4=1: you][S4=2/3 the individual receiving ESA or Universal Credit], we would like to double check that you are happy to proceed at this point?

ADD IF NECESSARY: Some of the questions are about work-related activities, such as [S4=1: your][S4=2/3 their], work history.

IF CATI: Happy to proceed: Does not have a terminal illness IF ONLINE: [S4=1: I do][S4=2/3 The person receiving ESA/UC does] not have a terminal illness	1	CONTINUE
IF CATI: Happy to proceed: Has a terminal illness, but happy to take part IF ONLINE: [S4=1: I have][S4=2/3 The person receiving ESA/UC has] a terminal illness and [S4=1: I am][S4=2/3: is] happy to proceed with the survey	2	ROUTE B: SECTION A, C, D, G, K AND M ONLY AND – FROM SECTION B AND J –QUESTION B1-B6 AND J4-6 ONLY
IF CATI: Does not want to proceed:Has a terminal illness IF ONLINE: [S4=1:I have] [S4=2/3 The person	3	
receiving ESA/UC has] a terminal illness and [S4=1: I do] [S4=2/3:does] not want to proceed with the survey		

ASK IF TERMINAL ILLNESS AND WOULD NOT LIKE TO TAKE PART (S3=3)

S3a Thank you for your time today. Would you be ok with us notifying the DWP of your prognosis so that they can update their records? This will ensure that they don't contact you for research purposes again.

Yes	1	THANK AND CLOSE
No	2	THANK AND CLOSE

ASK IF TERMINAL ILLNESS AND WOULDLIKE TO TAKE PART (S3=2)

S3b Thank you. Could I just check, would you be ok with us notifying the DWP of your prognosis so that they can update their records? This will ensure that you don't receive too many calls like this.

Yes	1	CONTINUE
No	2	CONTINUE

REASSURANCES TO USE IF NECESSARY

The interview will take around 30 minutes to complete

IF ASKS WHERE WE GOT CONTACT DETAILS: You have been chosen at random from contact details provided to us by the Department for Work and Pensions. The DWP are allowed to give us contact details to conduct research that is in the public interest because it will help them to improve the support that they offer.

The information you provide is treated in strict confidence and will not affect your dealings with the Department for Work and Pensions, nor any benefits you may be claiming.

If respondent wishes to confirm validity of IFF Research or get more information about aims and objectives, they can call: REDACTED

Online landing page

Thank you for your interest in this important study. By taking part, you'll be adding your voice to hundreds of other people to help DWP develop their services.

The Research is being carried out by IFF Research – an independent research company – on behalf of the Department for Work and Pensions (DWP).

For further information about the background to the research, or to find out what happens to the survey data we will collect from you as part of this interview, please see below.

To take part in the survey please click 'Next'. When completing the survey, please only use the 'Next' button on the page rather than the 'Back' and 'Forward' buttons in your browser.

Background to the research

IFF Research, an independent research company, has been commissioned by the Department of Work and Pensions (DWP) to carry out this survey to understand people's experiences of claiming Employment Support Allowance or Universal credit because of a disability or health condition and their support needs. By taking part, you'll be adding your voice to hundreds of other people to help DWP develop their services. Your details were selected at random from DWP's claimant records.

We would really like to hear about your views and experiences, but taking part in this survey is completely voluntary and you can refuse to answer individual questions or withdraw at any time. The interview is over the telephone and will last approximately 30 minutes.

What happens to the survey data?

Your answers may be linked to other information held by the Department for Work and Pensions so that they can analyse the results. However, the information you provide is treated in strict confidence and will not affect your dealings with the Department for Work and Pensions, nor any benefits you may be claiming. The research findings will be published online, but they will not identify you.

DWP collects and processes your survey responses to improve the services it provides as part of its public authority duty. The data from the survey will be held by DWP for 10 years. After this it will be securely destroyed.

If you would like further information about how DWP handles your information you can find this on the DWP's Personal Information Charter at: <u>https://www.</u> gov.uk/government/organisations/department-for-work-pensions/about/personalinformation-charter. You can also see more about your personal information rights on the Information Commissioner's Office website at: https://ico.org.uk.

ASK ALL

S5 And can I just confirm that [IF PERSON RECEIVING ESA/UC S4=1: you are] [IF APPOINTEE/CARER etc. S4=2/3: the person receiving ESA or UC is] currently either in the ESA support group or the equivalent Universal Credit group. By this we mean that [S4=1: you] [IF S4=2/3: they] have been assessed under Universal Credit as having limited capability for work-related activity because of a health condition or disability...?

IF RESPONDENT IS UNSURE, ADD IF NECESSARY: People in the ESA Support Group or the equivalent Universal Credit group will have gone through a Work Capability Assessment and been deemed as having limited capability for work or work-related activity. People in this group won't be asked to look for or prepare for work as part of their claim, won't be required to attend meetings at their local Jobcentre, and won't be expected to do any activities to help them prepare for work.

Yes: in ESA support group	1	
Yes: in equivalent UC group	2	
No	3	THANK AND CLOSE
Don't know [DS – EXCLUSIVE CODE]	4	THANK AND CLOSE
Prefer not to say [DS – EXCLUSIVE CODE]	5	THANK AND CLOSE

S5=3,4,5 THANK AND CLOSE TEXT: Thank you for your interest in this survey. Unfortunately, you are not eligible to take part in this research as we are only looking to hear from people in the ESA support group or the equivalent UC group.

ASK ALL IF NOT A FORMAL APPOINTEE AND TELEPHONE (S4=3 AND TEL INT)

S6 Finally, can we just confirm that you have permission from the person receiving ESA or UC to answer this questionnaire on their behalf?

Yes – Person receiving UC/ESA came to the phone and stated: <i>"I give permission for this person to answer on my behalf"</i>	1	CONTINUE
Yes – but person receiving UC/ESA not available to come to the phone right now	2	MAKE AN APPOINTMENT
No – Person receiving UC/ESA is not able to give their permission	3	ASK IF THERE IS A WAY THEY COULD GIVE PERMISSION AND PASS TO TEAM LEADER, TO REPORT BACK TO RESEARCH. THANK AND CLOSE
No – Person receiving UC/ESA has explicitly stated that they do not give their permission	4	THANK AND CLOSE

ASK IF NOT A FORMAL APPOINTEE AND ONLINE (S4=3 and ONLINE INT)

S7 Can we just confirm that you have permission from the person receiving ESA or UC to answer this questionnaire on their behalf?

Yes – "I have permission to answer the questionnaire on behalf of the person receiving UC/ESA"	1	CONTINUE
No – "I need to seek permission before I take part"	2	THANK AND CLOSE SCREEN TO READ: "Thank you. We would be very grateful if you could seek permission from the person receiving UC/ESA and – once you have it – come back and take part".
No – "The person receiving UC/ESA has explicitly stated that they do not give their permission"	3	THANK AND CLOSE SCREEN TO READ: Thank you for your time, however to respond to this survey you need to have permission from the person receiving UC/ESA

IF NOT PERSON RECEIVING ESA OR UC (S4=2 OR 3)

S8 Thank you. This survey has been designed as though we are speaking directly to the person receiving ESA or UC. Therefore, please answer the questions from the perspective of the person receiving ESA or UC, who we will refer to from now on as "your appointee".

REASSURANCES TO USE IF NECESSARY

The interview will take around 30 minutes to complete.

Please note that all data will be reported in aggregate form and your answers will not be reported to our client in any way that would allow you to be identified.

If respondent wishes to confirm validity of survey or get more information about aims and objectives, they can call: REDACTED

A Benefit History

ASK ALL

We'd like to start by finding out about the benefits [S4=1: you receive] [S4=2/3: your appointee receives].

ASK ALL CLAIMING ESA (S5=1)

A1 Roughly how long have you been in the Employment Support Allowance (ESA) support group?

SINGLECODE. PROMPT IF NECESSARY.

Less than 1 year	1	
1 – 3 years	2	
Over 3 years – 5 years	3	
Over 5 years – 10 years	4	
Over 10 years	5	
Don't know [DS – EXCLUSIVE CODE]	6	
Prefer not to say [DS – EXCLUSIVE CODE]	7	

ASK ALL CLAIMING UC (S5=2)

A2 Roughly how long have you been assessed as having limited capability for work and work-related activity under Universal Credit (UC)?

SINGLECODE. PROMPT IF NECESSARY.

Less than 6 months	1	
At least 6 months but less than 1 year	2	
1 – 3 years	3	
Over 3 years – 5 years	4	
Don't know [DS – EXCLUSIVE CODE]	5	
Prefer not to say [DS – EXCLUSIVE CODE]	6	

- A3 ASK ALL
- A4 In total, including your current benefit claim, for how long have you been receiving out of work benefits [IF UC FROM SAMPLE: and/or Universal Credit] because of a health condition or disability?

ADD IF NECESSARY: By 'out of work benefits' we mean Incapacity benefit, Employment support allowance (ESA), Severe Disablement Allowance and Industrial Injuries Disablement Benefit.

SINGLECODE. PROMPT IF NECESSARY.

Less than 1 year	1	
1-3 years	2	
Over 3 years – 5 years	3	
Over 5 years – 10 years	4	
Over 10 years – 15 years	5	
Over 15 years – 20 years	6	
More than 20 years	7	
Don't know [DS – EXCLUSIVE CODE]	8	
Prefer not to say [DS – EXCLUSIVE CODE]	9	

ASK ALL

A5 Do you currently receive any of the following benefits?

READ OUT. MULTICODE

Personal Independence Payment (PIP)	1	
Disability Living Allowance (DLA)	2	
Industrial Injuries Disablement Benefit (IIDB)	3	
Severe Disability Premium (SDP)	4	
None of these [DS – EXCLUSIVE CODE]	5	
Don't know [DS – EXCLUSIVE CODE]	6	
Prefer not to say [DS – EXCLUSIVE CODE]	7	

THERE IS NO A5.

ASK IF RECEIVE PIP OR DLA (A4 =1 OR 2)

A6 In which of the following ways do you use your [A4=1: PIP] [A4=1 AND 2: and] [A4=2: DLA] payment?

PROMPT IF NECESSARY. MULTICODE

For general household living expenses such as bills and groceries	1	
For additional travel costs associated with disability	2	
For specialist equipment, adaptations or assistive technologies	3	
For specialist or extra clothing associated with your health condition or disability	4	
To pay for carers	5	
To pay for help around the home	6	
For medical costs incl. therapies/treatments and medicines	7	
To take part in social activities	8	
To give gifts or treat people who help me	9	
Anything else, please specify	10	
Don't know [DS – EXCLUSIVE CODE]	11	
Prefer not to say [DS – EXCLUSIVE CODE]	12	

B Disability/Health Condition

ASK ALL CLAIMING ESA OR UC (S4=1)

B1 We'd like to ask you a few questions about your health and how this affects you on a day-to-day basis. This is to allow us to see whether people with different circumstances have different views. Please be assured that any information you provide will be held in the strictest confidence. You can refuse to answer any or all of these questions when we get to them.

ASK ALL APPOINTEES (S4=2 or 3)

Thank you for that, we're now going to ask some questions about your appointee's health and how this affects them on a day-to-day basis. This is to allow us to see whether people with different circumstances have different views. Please be assured that any information you provide will be held in the strictest confidence. You can refuse to answer any or all of these questions when we get to them. Just to remind you, please answer the questions about their health specifically.

Are you willing to proceed with this section of the interview, on this basis?

SINGLECODE

Yes	1	
Νο	2	

- B2 THERE IS NO B2.
- B3 THERE IS NO B3.

ASK ALL WHO GAVE PERMISSION (B1=1)

B4 Please can you tell me what health condition(s) you currently or have recently had?

PROMPT AS NECESSARY. MULTICODE.

ASK ALL MULTICODED AT B4

B4a And which of those would you consider to be your main health condition?

READ OUT. SINGLECODE

DS: SHOW ALL CODES SELECTED AT B4.

Mental Health Conditions		
Stress or anxiety	1	
Depression	2	
Bipolar disorder	3	
Psychotic disorder or Schizophrenia	4	
Other, please specify:		
MH CONDITION 1:	5	

Conditions related to bones, muscle problem	ms or physical injury
Problems with your arms or hands	6
Problems with your legs or feet	7
Problems with your neck, shoulders or back	8
Pain or discomfort	9
Any other condition related to bone or	
muscle problems or physical injury (please specify)	10
BMP CONDITION 1:	
Long-term conditions that affect major orga	ins or the whole body
Problems with your bowel, stomach, liver, kidneys or digestion including Crohn's disease	11
Chest or breathing problems including asthma	12
Heart problems or blood pressure including angina	13
Skin conditions or allergies	14
Cancer	15
Other long-term condition (please specify)	10
LT CONDITION 1:	16
Other condition or disability	
Fatigue or problems with concentration or memory	17
Difficulty in seeing (while wearing glasses or contact lenses)	18
Difficulty in hearing	19
Speech problems	20
Dizziness or balance problems	21
Diabetes	22
Problems due to drug or alcohol addiction	23
Epilepsy	24
Learning difficulties including dyslexia	25
Learning disabilities (INTERVIEWER NOTE:	
This is different to a learning difficulty and means an individual may need care and support with day-to-day activities such as washing, dressing, cooking, going out and communication)	26
Asperger's syndrome or autism	27
Progressive illness not covered above	28

Other health problem or disability (please specify)	29	
OTHER CONDITION 1:		
OTHER CONDITION 2:	30	
OTHER CONDITION 3:	31	
OTHER CONDITION 4:	32	
OTHER CONDITION 5:	33	
OTHER CONDITION 6:	34	
OTHER CONDITION 7:	35	
B4a ONLY – DO NOT READ OUT: Cannot distinguish main health condition	36	
Don't know [DS – EXCLUSIVE CODE]	37	
Prefer not to say [DS – EXCLUSIVE CODE]	38	

ASK ALL WHO CONSENTED (B1 = 1)

B5 [B4a=1-29, 32: Thinking about your main health condition, when did it begin...?] [B4a=30 or 31: When did you first start experiencing these health issues?] [B4=SINGLE CODE: Thinking about this health condition, when did it begin?]

PROMPT AS NECESSARY. SINGLECODE

At birth	1	
During childhood	2	
During Teenage years	3	
During adulthood	4	
Don't know [DS – EXCLUSIVE CODE]	5	
Prefer not to say [DS – EXCLUSIVE CODE]	6	

ASK ALL WHO CONSENTED (B1 = 1)

B6 Would you say that [IF ONE ANSWER GIVEN AT B4: your health condition fluctuates] [IF MORE THAN ONE ANSWER GIVEN ACROSS AT B4: any of your health conditions are ones that fluctuate]; that is, you have good and bad days, weeks or months with it?

SINGLECODE

Yes	1	
No	2	
Don't know [DS – EXCLUSIVE CODE]	3	
Prefer not to say [DS – EXCLUSIVE CODE]	4	

QUESTION B7 HAS BEEN MOVED TO AFTER B8

ASK ALL WHO CONSENTED (B1 = 1)

B8 Now, thinking about the future,[IF B6=1: – setting aside any temporary good or bad days, weeks or months –] do you expect your health conditions to improve, stay the same or get worse?

DO NOT READ OUT. SINGLECODE

Improve	1	
Stay the same	2	
Get worse	3	
Don't know [DS – EXCLUSIVE CODE]	4	
Prefer not to say [DS – EXCLUSIVE CODE]	5	

ASK ALL WHO CONSENTED (B1 = 1)

B7 And again, [IF B6=1: -setting aside any temporary good or bad days, weeks or months -] how long do you expect your health condition(s) to last?

PROMPT AS NECESSARY. SINGLECODE

For the rest of my life	1	
Less than a year	2	
1 – 3 years	3	
4 – 5 years	4	
6 – 10 years	5	
11 years or more	6	
Don't know [DS – EXCLUSIVE CODE]	7	
Prefer not to say [DS – EXCLUSIVE CODE]	8	

C General Well-being⁶¹

READ OUT TO ALL: We'd now like to ask some questions about [S4=1: your health and wellbeing] [S4=2/3: the health and wellbeing of your appointee. To remind you, these questions have been designed as though we are speaking directly with your appointee. As always, please answer these questions about their condition specifically]. This is to help us understand [S4=1: your] [S4=2/3: their] circumstances and whether different people have different views.

ADD IF NECESSARY: Please be assured that any information you provide will be held in the strictest confidence, and if there are any of these questions that you'd prefer not to answer, that's fine.

ASK ALL

C1 The next three statements are about your mobility. Please can you tell me which best applies to you today?

READ OUT. SINGLECODE

You have no problem in walking about	1	
You have some problems in walking about	2	
You are confined to bed	3	
Don't know [DS – EXCLUSIVE CODE]	4	
Prefer not to say [DS – EXCLUSIVE CODE]	5	

ASK ALL

C2 And the next three statements are about your self-care. By this we mean washing and dressing yourself. Again, please can you tell me which applies to you today?

READ OUT. SINGLECODE

You have no problems with self-care	1	
You have some problems washing or dressing yourself	2	
You are unable to wash or dress yourself	3	
Don't know [DS – EXCLUSIVE CODE]	4	
Prefer not to say [DS – EXCLUSIVE CODE]	5	

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ASK ALL

C3 The next three statements are about your usual activities so things like housework, family activities or leisure activities. Which of these best applies to you today?

READ OUT. SINGLECODE

You have no problems with performing your usual activities	1	
You have some problems performing your usual activities	2	
You are unable to perform your usual activities	3	
Don't know [DS – EXCLUSIVE CODE]	4	
Prefer not to say [DS – EXCLUSIVE CODE]	5	

ASK ALL

C4 And in terms of your levels of pain or discomfort. Which of these best applies to you today?

READ OUT. SINGLECODE

You have no pain or discomfort	1	
You have moderate pain or discomfort	2	
You have extreme pain or discomfort	3	
Don't know [DS – EXCLUSIVE CODE]	4	
Prefer not to say [DS – EXCLUSIVE CODE]	5	

ASK ALL

C5 And in terms of anxiety or depression. Which of these best applies to you today?

READ OUT. SINGLECODE

You are not anxious or depressed	1	
You are moderately anxious or depressed	2	
You are extremely anxious or depressed	3	
Don't know [DS – EXCLUSIVE CODE]	4	
Prefer not to say [DS – EXCLUSIVE CODE]	5	

D Work History

READ OUT TO ALL: The next few questions are about what experiences [S4=1: you have] [S4=2/3: your appointee has] had of work.

Please be assured, we simply want to understand a bit more about [S4=1: your] [S4=2/3: their] employment history. If [S4=1: you] [S4=2/3: they] do not have any experience of work then this is fine.

ADD IF NECESSARY: Your responses are confidential and will not affect [S4=1: your] [S4=2/3: their] benefits or dealings with the Department for Work or Pensions in any way.

- D1 THERE IS NO D1.
- D2 THERE IS NO D2.

ASK ALL

D4 Which of the following statements best describes your work history? By 'working' we also mean part-time work or self-employment – not just full-time employment.

READ OUT. SINGLECODE

I have never been in paid employment	1	
I have mostly been out of paid employment	2	
I have been in and out of paid employment	3	
I have mostly been in paid employment or self-employment during my working life	4	
Don't know [DS – EXCLUSIVE CODE]	5	
Prefer not to say [DS – EXCLUSIVE CODE]	6	

ASK THOSE WHO HAVE WORKED BEFORE D4=2/3/4

D2a Thinking about the last paid job that you had, how long ago did you last work in this job...?

SINGLE CODE. PROMPT AS NECESSARY.

N/a: Currently in work	1	
Less than 6 months ago	2	
Between 6 months and less than 1 year ago	3	
Between 1 year and less than 3 years ago	4	
Between 3 years and less than 5 years ago	5	
Between 5 years and less than 10 years ago	6	
Between 10 years and less than 15 years	7	
ago		
Between 15 years and less than 20 years	8	
ago	Ŭ	
More than 20 years ago	9	
Don't know [DS – EXCLUSIVE CODE]	10	
Prefer not to say [DS – EXCLUSIVE CODE]	11	

ASK THOSE WHO HAVE WORKED BEFORE D4=2/3/4

D3 And in your most recent paid role, [IF D2a=1: are] [D2a ≠1: were] you in... READ OUT. SINGLECODE

Full-time paid work (more than 30 hours per week)	1	
Part-time paid work between 16 and 30 hours per week	2	
Part-time paid work up to 15 hours per week	3	
Self-employed paid work or starting your own business	4	
Don't know [DS – EXCLUSIVE CODE]	5	
Prefer not to say [DS – EXCLUSIVE CODE]	6	

ASK ALL

D5 Have you ever done any volunteering or voluntary work and if you have, when?

SINGLECODE. PROMPT AS NECESSARY.

No, never	1	
Yes, still undertaking this work	2	
Yes, finished less than 6 months ago	3	
Yes, finished between 6 months and less than 1 year ago	4	
Yes, finished between 1 year and less than 2 years ago	5	
Yes, finished between 2 years and less than 5 years ago	6	
Yes, finished 5 years ago or more	7	
Don't know [DS – EXCLUSIVE CODE]	8	
Prefer not to say [DS – EXCLUSIVE CODE]	9	

E Attitudes towards work in the future/work aspirations and steps towards work

READ OUT TO ALL: We'd now like to understand how [S4=1: you feel] [S4=2/3: your appointee feels] about working either now or in the future. [S4=2/3: To remind you, please answer these questions on their behalf and from their perspective.]

Please be assured, we simply want to understand what [S4=1: your] [S4=2/3: your appointee's] current position is to ensure we have a full picture. If [S4=1: you] [S4=2/3: they] have no intention or desire to go into work that is fine.

ADD IF NECESSARY: Your responses are confidential and will not affect [S4=1: your] [S4=2/3: their] benefits or dealings with the Department for Work or Pensions in any way.

ASK ALL EXCEPT THOSE IN PAID WORK (ALL EXCEPT D2A=1)

E1 Which of the following is closest to how you <u>currently</u> feel about paid work? Again, by 'working' we also mean part-time work or selfemployment – not just full-time employment.

READ OUT. SINGLECODE

My health condition/disability rules out work as an option now and in the future	1	
I am currently unable to work, but might be able to in the future if my health condition/ disability improves	2	
I could return to work now if the right job was available or if I had the right support	3	
Don't know [DS – EXCLUSIVE CODE]	4	
Prefer not to say [DS – EXCLUSIVE CODE]	5	

ASK ALL IN WORK D2A=1

E1a Which of the following is the closest to how you currently feel about the paid work you are in?

READ OUT. SINGLECODE

I am currently doing the amount of paid work I want to do	1	
My current paid work is a stepping stone to the work I ideally want to do	2	
Other, please specify	3	
Don't know [DS – EXCLUSIVE CODE]	4	
Prefer not to say [DS – EXCLUSIVE CODE]	5	

ASK ALL WHOSE HEALTH CONDITION DOES NOT RULE OUT WORKING, EXCEPT THOSE IN PAID WORK (ALL UNLESS E1=1 OR D2A=1)

E2 To what extent would you like to undertake paid work in the future, whether this is full-time work, part-time work or self-employment?

READ OUT. SINGLECODE

Not at all	1	
A little	2	
To some extent	3	
To a great extent	4	
Don't know [DS – EXCLUSIVE CODE]	5	
Prefer not to say [DS – EXCLUSIVE CODE]	6	

ASK IF WOULD LIKE TO UNDERTAKE PAID WORK (E2=2/3/4) OR IF CURRENTLY IN PAID WORK (D2A=1)

E3 [D2a=1: And thinking about the future, which of the following types of paid work would you like to do?] [E2=2/3/4: And which of the following types of paid work are you interested in doing?]

READ OUT. SINGLECODE

Full-time paid work (more than 30 hours per week)	1	
Part-time paid work between 16 and 30 hours per week	2	
Part-time paid work up to 15 hours per week	3	
Self-employed paid work or starting your own business	4	
Don't know [DS – EXCLUSIVE CODE]	5	
Prefer not to say [DS – EXCLUSIVE CODE]	6	

ASK IF WOULD LIKE TO UNDERTAKE PAID WORK (E2=2/3/4)

E4 At what stage in the future, if ever, do you think you will be able to undertake paid work. Would you say...

Never	1	
Within the next six months	2	
Within the next year	3	
Within the next two years	4	
Later than two years	5	
Don't know [DS – EXCLUSIVE CODE]	6	
Prefer not to say [DS – EXCLUSIVE CODE]	7	

READ OUT IF E1=1 AND D5≠2: We understand that you have said that [S4=1: your] [S4=2/3: your appointee's] health condition/disability rules out work as an option now and in the future. We'd now like to ask you how you feel about volunteering or doing voluntary work. So...

READ OUT IF E2=1 AND D5≠2: We understand that you have said that [S4=1: you are] [S4=2/3: your appointee is] not at all interested in paid work. We'd now like to ask you how you feel about volunteering or doing voluntary work. So...

ASK ALL EXCEPT THOSE CURRENTLY IN VOLUNTARY WORK (ALL EXCEPT D5=2)

E5 If you knew it would not affect your benefits in any way, to what extent would you be interested in volunteering or doing voluntary work in the future?

Not at all	1	
A little	2	
To some extent	3	
To a great extent	4	
Don't know [DS – EXCLUSIVE CODE]	5	
Prefer not to say [DS – EXCLUSIVE CODE]	6	

READ OUT. SINGLECODE

E6 THERE IS NO E6.

ASK IF WOULD LIKE TO UNDERTAKE VOLUNTARY WORK (E5=2/3/4)

E7 And at what stage in the future, if ever, do you think you might be able to volunteer or undertake voluntary work?. Would you say...

Never	1	
Within the next six months	2	
Within the next year	3	
Within the next two years	4	
Later than two years	5	
Don't know [DS – EXCLUSIVE CODE]	6	
Prefer not to say [DS – EXCLUSIVE CODE]	7	

F Barriers to work – challenges and needs

READ OUT IF E1=1: you have told us that [S4=1: your] [S4=2/3: your appointee's] health condition/disability rules out work as an option now and in the future. We'd like to ask you some more questions to understand how [S4=1:your] [S4=2/3: your appointee's] health condition affects how [E1=1: you] [E1=2/3: they] feel about working. You may feel that some of these statements don't apply to your [S4=2/3: appointee's] situation, but it would be very helpful though if you could agree or disagree where possible. If you feel strongly that none of statements apply then that is fine.

READ OUT IF E2=1: We understand that you have said that [S4=1: you are] [S4=2/3: your appointee is] not at all interested in paid work. We'd like to ask you some more questions to understand how [S4=1:your] [S4=2/3: your appointee's] health condition affects how [E1=1: you] [E1=2/3: they] feel about working. You may feel that some of these statements don't apply to your [S4=2/3: appointee's] situation, but it would be very helpful though if you could agree or disagree where possible If you feel strongly that none of statements apply then that is fine.

READ OUT TO ALL OTHERS UNLESS D2a=1: We are now going to ask you about how much you agree or disagree with a series of statements. You may feel that some of these statements don't apply to your [S4=2/3: appointee's] situation, it would be very helpful though if you could agree or disagree where possible.

ADD IF NECESSARY: UNLESS D2a=1: To remind you, your responses are confidential and will not affect [S4=1: your] [S4=2/3: your appointees] benefits or dealings with the Department for Work or Pensions in any way.

ASK ALL EXCEPT THOSE IN PAID WORK (ALL EXCEPT D2A=1)

F1 On a scale of 1 to 5 where 1 is strongly disagree and 5 is strongly agree, to what extent [S4=1 do you] [S4=2/3: do you think your appointee would] agree or disagree with the following statements about [S4=1: your] [S4=2/3: their] health condition/disability and [S4=1: your] [S4=2/3: their] feelings about finding work?

READ OUT. CODE ONE PER ROW.

DS: PLEASE ROTATE STATEMENTS

		Strong	ıly disa			Don't Know	Prefer not to say	E1=1:Not applicable: I will never be in a position to work again	E1=1 & telephone: INTERVIEWER- LED: Not applicable: Respondent condition is severe, questions are causing distress/ annoyance, SKIP
1 I am worried people won't employ me because of my health condition	1	2	3	4	5	6	7	8	9
2 I am worried that working could make my health condition worse	1	2	3	4	5	6	7	8	9
5 Managing my health condition/ disability means I don't have time to work	1	2	3	4	5	6	7	8	9
6 My health condition/ disability fluctuates too much for me to work	1	2	3	4	5	6	7	8	9

ASK ALL EXCEPT THOSE IN PAID WORK (ALL EXCEPT D2A=1)

F2 And again, on a scale of 1 to 5 where 1 is strongly disagree and 5 is strongly agree, to what extent [S4=1 do you] [S4=2/3: do you think your appointee would] agree or disagree with the following statements about [S4=1: your] [S4=2/3: their] health condition/disability and[S4=1: your] [S4=2/3: their] feelings about finding work?

READ OUT. CODE ONE PER ROW.

DS: PLEASE ROTATE STATEMENTS

						Don't Know	Prefer not to say	E1=1:Not applicable: I will never be in a position to work again	E1=1 & telephone: INTERVIEWER- LED: Not applicable: Respondent condition is severe, questions are causing distress/ annoyance, SKIP
2 I think employers could accommodate my health needs	1	2	3	4	5	6	7	8	9
3 I know how to present myself and my health condition or disability in my CV or at interviews	1	2	3	4	5	6	7	8	9
4 Having a job would be beneficial for my health	1	2	3	4	5	6	7	8	9

ASK ALL EXCEPT THOSE IN PAID WORK (ALL EXCEPT D2A=1)

F3 Again, on a scale of 1 to 5 where 1 is strongly disagree and 5 is strongly agree, to what extent [S4=1 do you] [S4=2/3: do you think your appointee would] you agree or disagree with the following statements about [S4=1: your] [S4=2/3: their] health condition/disability and [S4=1: your] [S4=2/3: their] feelings about finding work?

READ OUT. CODE ONE PER ROW.

DS: PLEASE ROTATE STATEMENTS

			gly disa			Don't Know	Prefer not to say	E1=1:Not applicable: I will never be in a position to work again	E1=1 & telephone: INTERVIEWER- LED: Not applicable: Respondent condition is severe, questions are causing distress/ annoyance, SKIP
1 I have other personal or family issues that need to be sorted out before I can consider working, e.g. debt or housing issues	1	2	3	4	5	6	7	8	9
3 I don't have the right qualifications, skills or experience	1	2	3	4	5	6	7	8	9
4 I don't know what suitable jobs are available	1	2	3	4	5	6	7	8	9
5 I don't feel confident about applying for jobs	1	2	3	4	5	6	7	8	9

ASK ALL EXCEPT THOSE IN PAID WORK (ALL EXCEPT D2A=1)

F4 And again, on a scale of 1 to 5 where 1 is strongly disagree and 5 is strongly agree, to what extent [S4=1 do you] [S4=2/3: do you think your appointee would] you agree or disagree with the following statements about [S4=1: your] [S4=2/3: their] health condition/disability and [S4=1: your] [S4=2/3: their] feelings about finding work?

READ OUT. CODE ONE PER ROW.

DS: PLEASE ROTATE STATEMENTS.

			gly disa			Don't Know	Prefer not to say	E1=1:Not applicable: I will never be in a position to work again	E1=1 & telephone: INTERVIEWER- LED: Not applicable: Respondent condition is severe, questions are causing distress/ annoyance, SKIP
1 I'm worried people won't employ me because of my age	1	2	3	4	5	6	7	8	9
2 I may find it difficult to travel to work with my health condition	1	2	3	4	5	6	7	8	9
3 I have family or caring responsibilities that make working difficult	1	2	3	4	5	6	7	8	9
5 I am worried that I wouldn't get my benefits back if I try paid employment and then it doesn't work out	1	2	3	4	5	6	7	8	9

ASK IF F4_3 = 4/5

F5 You indicated that [S4=1: you have] [S4=2/3: your appointee has] family or caring responsibilities that make working difficult...Who do [S4=1: you] [S4=2/3: they] have caring responsibilities for?

PROMPT AS NECESSARY. MULTICODE

[S4=1: My] [S4=2/3: their] child(ren)	1	
[S4=1: My] [S4=2/3: their] partner	2	
[S4=1: My] [S4=2/3: their] parents/ grandparents	3	
Other family member	4	
A friend	5	
Other (PLEASE SPECIFY)	6	
Don't know [DS – EXCLUSIVE CODE]	7	
Prefer not to say [DS – EXCLUSIVE CODE]	8	

IF CODE 9 AT ANY F1-4

F6 INTERVIEWER:PLEASE BRIEFLY OUTLINE WHY YOU NEEDED TO SKIP THIS/THESE STATEMENTS

WRITE IN

G Receipt of informal/formal support

READ OUT TO ALL: The next question is about the types of support [S4=1: you receive to do with your health condition or disability.By support, we mean any help you might receive from professionals, support organisations or community groups, family or friends.] [S4=2/3: your appointee receives to do with their health condition or disability. By support, we mean any help they might receive from professionals, support organisations or community groups, family or friends. To remind you, these questions have been designed as though we are speaking directly with your appointee, please answer from their perspective.]

ASK ALL

G1 Are you <u>currently</u> receiving support for your health condition or disability from any of the following?

READ OUT. MULTICODE

A carer, a relative or friend	1	
Your family doctor or GP	2	
Hospital/specialist medical support	3	
An outpatients clinic	4	
A mental health worker	5	
A counsellor or therapist	6	
Another health professional	7	
A specialist health-related charity	8	
A support worker	9	
Someone else (please specify)	10	
None of the above [EXCLUSIVE CODE]	11	
Need support but not accessed any [EXCLUSIVE CODE]	12	
No support needed [EXCLUSIVE CODE]	13	
Don't know [DS – EXCLUSIVE CODE]	14	
Prefer not to say [DS – EXCLUSIVE CODE]	15	

H Support needs/wants re work including health-related needs & any other key barriers

READ OUT TO ALL: We'd now like to find out if [S4=1: you are] [S4=2/3: your appointee is] receiving any support to help [S4=1: you] [S4=2/3: them] [ALL EXCEPT D2a=1: move closer to being able to work] [D2a=1: progress in work], or if this is something [S4=1: you] [S4=2/3: they] might be interested in receiving.

READ OUT IF E1=1: We understand that you have said that [S4=1: your] [S4=2/3: your appointee's] health condition/disability rules out work as an option now and in the future, so if you feel none of this is relevant that is of course fine.

READ OUT IF E2=1: We understand that you have said that [S4=1: you are] [S4=2/3: your appointee is] not at all interested in paid work, so if you feel none of this is relevant that is of course fine.

ADD IF NECESSARY: To remind you, your responses are confidential and will not affect [S4=1: your] [S4=2/3: your appointees] benefits or dealings with the Department for Work or Pensions in any way.

ASK ALL

H1 Are you currently receiving any help or support that is helping you to [D2a=1: progress in work] [ALL OTHERS: move closer towards to work?] By this we mean help with things like building your confidence or skills, help with CVs [ALL EXCEPT D2a=1: or finding suitable work] [D2a=1: to help you progress in work].

SINGLECODE

Yes	1	
No	2	
Don't know [DS – EXCLUSIVE CODE]	3	
Prefer not to say [DS – EXCLUSIVE CODE]	4	
E1=1 DO NOT READ OUT: Not applicable: I will never be in a position to work again'	5	
E1=1 & telephone: INTERVIEWER-LED: Not applicable: Respondent condition is severe, questions are causing distress/annoyance, SKIP	6	

ASK IF CURRENTLY RECEIVING SUPPORT (H1 = 1)

H2 Which of the following forms of support are you currently receiving to help you [D2a=1: to progress in work] [ALL OTHERS: to move closer to work?]

READ OUT. MULTICODE.

Help with finding volunteering opportunities or voluntary work	1	
Help with finding suitable work experience	2	
Help with finding suitable work and suitable employers	3	
Information and advice about what sort of work you could do	4	
Help to develop your skills e.g. through training courses	5	
Support with how to present yourself in CVs and interviews	6	
Help with managing money, debt or benefits	7	
Help with building confidence, self-esteem or getting into a routine	8	
Anything else (PLEASE SPECIFY)	9	
Don't know [DS – EXCLUSIVE CODE]	10	
Prefer not to say [DS – EXCLUSIVE CODE]	11	

ASK IF CURRENTLY RECEIVING SUPPORT (H1 = 1)

H3 What individuals, organisations or groups are providing this support? PROMPT AS NECESSARY. MULTICODE.

A carer, relative or friend	1	
Your family doctor or GP	2	
A mental health worker	3	
A counsellor or therapist	4	
Another health professional	5	
A charity worker from an organisation linked to your health condition/disability	6	
A charity worker from an organisation not linked to your health condition/disability	7	
JobCentre Adviser or Work Coach	8	
An employment agency	9	
An individual at a college or other education institution	10	
A previous employer	11	
A support worker	12	
Someone else (please specify)	13	
None of these [DS – EXCLUSIVE CODE]	14	
Don't know [DS – EXCLUSIVE CODE]	15	
Prefer not to say [DS – EXCLUSIVE CODE]	16	

ASK ALL

H4 On a scale of 1 to 5, where 1 means not at all interested, and 5 means very interested, how interested would you be in receiving the following types of support to help you [D2a=1: progress in work] [ALL OTHERS: move closer to work]?

READ OUT. CODE ONE PER ROW.

	Not a intere			inter	Very ested	Prefer not to say	Don't know	E1=1:Not applicable: I will never be in a position to work again	E1=1 & telephone: INTERVIEWER- LED: Not applicable: Respondent condition is severe, questions are causing distress/ annoyance, SKIP
7 Advice or guidance about what sorts of jobs you could do [if D2a=1: in the future]	1	2	3	4	5	6	7	8	9
1 Help with finding suitable work and suitable [if D2a=1:future] employers	1	2	3	4	5	6	7	8	9
6 Help with finding volunteering opportunities, voluntary work or work experience [if D2a=1: in the future]	1	2	3	4	5	6	7	8	9
10 Wider support with other issues in your life such as debt, managing your finances or housing	1	2	3	4	5	6	7	8	9

	Not a intere			inter	Very ested	Prefer not to say	Don't know	E1=1:Not applicable: I will never be in a position to work again	E1=1 & telephone: INTERVIEWER- LED: Not applicable: Respondent condition is severe, questions are causing distress/ annoyance, SKIP
9 Help with how to present yourself in CVs and interviews [if D2a=1: in the future]	1	2	3	4	5	6	7	8	9
4 Help with understanding disabled people's legal rights to do with working	1	2	3	4	5	6	7	8	9
8 Help communicating your health condition and support needs to employers	1	2	3	4	5	6	7	8	9
5 Help with the costs of [ALL EXCEPT D2a=1: starting work] [D2a=1: starting a new job or position] (e.g. helping you to pay for transport or clothing)	1	2	3	4	5	6	7	8	9
2 Support from a dedicated support worker, to resolve any problems when you start a new job [if D2a=1: in the future]	1	2	3	4	5	6	7	8	9

IF (CODE 6 AT H1 OR CODE 9 AT EITHER OR H4) AND NOT CODE 9 AT ANY F1-4

H5 INTERVIEWER: PLEASE BRIEFLY OUTLINE WHY YOU NEEDED TO SKIP THIS/THESE STATEMENTS

WRITE IN

I THERE IS NO SECTION I.

J Engagement/communication with DWP/JCP

READ OUT TO ALL: We'd now like to find out how S4=1: you feel] [S4=2/3: your appointee feels] about the Department for Work & Pensions or JobCentre Plus contacting [S4=1: you] [S4=2/3: them] to let [S4=1: you] [S4=2/3: them] know about the support they offer.

S4=2/3: IF NECESSARY: To remind you, please answer from the perspective of your appointee.

ASK ALL

J2 Roughly, how often do you feel it would it be appropriate for <u>Department</u> for Work & Pensions or Jobcentre Plus to get in touch with you about offering support?

Never	10	
More than once a month	1	
Once a month	2	
Once every three months	3	
Once every six months	4	
Once every year	5	
Once every couple of years	6	
Less than once every couple of years	7	
Don't know [DS – EXCLUSIVE CODE]	8	
Prefer not to say [DS – EXCLUSIVE CODE]	9	

ASK ALL EXCEPT J2=10

J1 And if the <u>Department for Work & Pensions or Jobcentre Plus</u> wanted to get in touch with you to let you know about the help they provide and to offer you support, which of the following ways of getting in touch would you prefer?

READ OUT. MULTICODE.

A letter	1	
An email	2	
A phone call	3	
A text message	4	
Other (please specify)	5	
None of the above [DS – EXCLUSIVE CODE]	6	
Don't know [DS – EXCLUSIVE CODE]	7	
Prefer not to say [DS – EXCLUSIVE CODE]	8	

ASK ALL

J3 And, on a scale of 1 to 5 where 1 is strongly disagree and 5 is strongly agree, to what extent do you agree or disagree with the following statements about either the Department for Work and Pensions or JobCentre Plus contacting you?

READ OUT. CODE ONE PER ROW.

	Strongly disagree	Tend to disagree	Neither agree nor disagree	Tend to agree	Strongly agree	Don't Know
1 I'd feel under too much pressure if they contacted me about support they offer	1	2	3	4	5	6
2 I'd be pleased if they contacted me about support they offer as it would show they'd not forgotten about me	1	2	3	4	5	6

READ OUT TO ALL: The next couple of questions are about your [S4=2/3: appointee's] use of the internet. [S4=2/3: To remind you, the questions have been designed as though we are speaking directly with your appointee].

ASK ALL

J4 Do you have access to the internet in any of the following ways...

READ OUT. MULTICODE

At home via a computer	1	
Through a mobile phone	2	
Regular access (once a week or more) on a computer somewhere other than your home (e.g. through friends or family or the local library)	3	
Irregular access (less than once a week) on a computer somewhere other than your home	4	
No access to the internet	5	
Don't know [DS – EXCLUSIVE CODE]	6	
Prefer not to say [DS – EXCLUSIVE CODE]	7	

ASK ALL

J6 And which of the following statements best describes your confidence with using the Internet?

I feel unable to use the internet	1	
I struggle with using the internet	2	
I can use the internet, but only for specific tasks	3	
I have a basic set of digital skills which allow me to use the internet	4	
I can confidently use the internet	5	
I'm an expert user of the internet	6	
Don't know [DS – EXCLUSIVE CODE]	7	
Prefer not to say [DS – EXCLUSIVE CODE]	8	

K Demographics

READ OUT TO ALL: The next few questions are about [S4=1: you] [S4=2/3: your appointee] and are for classification purposes only. All information you provide is held in the strictest of confidence.

ASK ALL

K1 What was your [S4=2/3: appointee's] age at [S4=1: your] [S4=2/3: their] last birthday?

WRITE IN

WRITE IN		
Don't know [DS – EXCLUSIVE CODE]	1	
Prefer not to say [DS – EXCLUSIVE CODE]	2	

IF DON'T KNOW EXACT NUMBER – PROMPT WITH RANGES

18-24	1	
25-29	2	
30-34	3	
35-39	4	
40-44	5	
45-49	6	
50-54	7	
55-59	8	
60-64	9	
65+	10	
Don't know [DS – EXCLUSIVE CODE]	11	
Prefer not to say [DS – EXCLUSIVE CODE]	12	

ASK ALL

K2 Please could we take down your [S4=2/3: appointee's] postcode? This will only be used to classify whether [S4=1: you] [S4=2/3: they] are living in a rural or urban, industrialised or non-industrialised area and to compare different regions, and will not be used for any other purposes.

INTERVIEWER NOTE. PLEASE TRY AND GET A FULL POSTCODE WHERE POSSIBLE.

WRITE IN

WRITE IN		
Don't know [DS – EXCLUSIVE CODE]	1	
Prefer not to say [DS – EXCLUSIVE CODE]	2	

ASK ALL

K7 And [S4=1: do you] [S4=2/3: does your appointee] have any dependent children, i.e. children that are aged under 19 and in full-time education?

SINGLECODE

Yes	1	
No	2	
Don't know [DS – EXCLUSIVE CODE]	3	
Prefer not to say [DS – EXCLUSIVE CODE]	4	

ASK ALL

K8 Thinking about where [S4=1: you live] [S4=2/3: your appointee lives], [S4=1: do you (or your household)] [S4=2/3: does your appointee (or their household)] own or rent [S4=1: your] [S4=2/3: their] accommodation?

Own it outright	1	
Buying it with the help of a mortgage/loan	2	
Part own and part rent (shared ownership)	3	
Rent it (includes all those who are on Housing Benefit or Local Housing Allowance)	4	
Live rent free (including rent-free in relative's/friend's property but excluding squatters)	5	
Squatting	7	
Paying rent to relatives/friends	8	
Don't know [DS – EXCLUSIVE CODE]	9	
Prefer not to say [DS – EXCLUSIVE CODE]	10	

ASK ALL

K9 And thinking about [S4=1: your] [S4=2/3: their] education, what is the highest qualification [S4=1: you] [S4=2/3: they] have achieved?

INTERVIEWER NOTE: PROMPT AS NECESSARY

SINGLE CODE.

	1	
Entry level qualification, for example Entry level certificates,Skills for Life at Entry level, Entry level awards, certificates and diplomas, Foundation Learning Tier pathways, Functional Skills at Entry level	1	
LEVEL 1 qualifications, for example GCSEs graded D-G, NVQs at level 1, Key Skills level , Skills for Life, Foundation Diploma, BTEC awards, certificates and diplomas at level 1, Functional Skills level 1, OCR Nationals, Foundation Learning Tier pathways	2	
LEVEL 2 which includes 5 GCSEs Grades A*- C, GCEs O Level,CSEs Grade 1, NVQ Level 2, Level 2 VQs, Key Skills Level 2, Skills for Life, Higher Diploma, BTEC awards, certificates and diplomas at level 2, Functional Skills level 2	3	
LEVEL 3 which includes 2 A levels, 3 AS levels, Advanced Extension Awards, International Baccalaureate, Key Skills level 3,NVQs at level 3, Cambridge International Awards, Advanced and Progression Diploma, BTEC awards, certificates and diplomas at level 3, BTEC Nationals, OCR Nationals	4	
LEVEL 4 which covers NVQs at level 4, Key Skills level 4, Certificates of higher education, BTEC Professional Diplomas, Certificates and Awards	5	
LEVEL 5 or above which covers undergraduate degrees (BSc, BA etc.), HNDs, Postgraduate certificates and diplomas, BTEC Professional Diplomas, Certificates and Awards,BTEC advanced professional awards, certificates and diplomas, Fellowships and fellowship diplomas, diplomas in Higher Education	6	
Don't know/Prefer not to say	7	
No formal qualifications	8	

ASK ALL

K3 We'd like to record your [S4=2/3: Appointee's] gender; ethnicity; and partnership status – again, for classification reasons only. This information will be held in the strictest confidence, and you can refuse to answer any or all of these questions when we get to them. This should only take a few more minutes. Is this ok?

SINGLECODE

Yes	1	
No	2	
Don't know [DS – EXCLUSIVE CODE]	3	

ASK IF CONSENTED K3 = 1

K4 What is your [S4=2/3: appointee's] gender?

SINGLECODE

Male	1	
Female	2	
Unspecified	3	
Don't know [DS – EXCLUSIVE CODE]	4	
Prefer not to say [DS – EXCLUSIVE CODE]	5	

ASK IF CONSENTED K3 = 1

K5 How would you describe your [S4=2/3: appointee's] ethnic background? SINGLE CODE. PROMPT AS NECESSARY.

WHITE British	1	
WHITE Irish	2	
WHITE Other background (SPECIFY)	3	
MIXED White and Black Caribbean	4	
MIXED White and Black African	5	
MIXED White and Asian	6	
MIXED Other mixed background (SPECIFY)	7	
BLACK OR BLACK BRITISH Caribbean	8	
BLACK OR BLACK BRITISH African	9	
BLACK OR BLACK BRITISH Other	10	
background (PLEASE SPECIFY)		
ASIAN OR ASIAN BRITISH Indian	11	
ASIAN OR ASIAN BRITISH Pakistani	12	
ASIAN OR ASIAN BRITISH Bangladeshi	13	
ASIAN OR ASIAN BRITISH Other background (PLEASE SPECIFY)	14	
CHINESE	15	
OTHER ETHNIC BACKGROUND (PLEASE SPECIFY)	16	
DO NOT READ OUT, DS EXCLUSIVE CODE: Don't know/Prefer not to say	17	

ASK IF CONSENTED K3 = 1

K6 Can we just check [S4=1: are you] [S4=2/3: is your appointee] living with someone in S4=1: your][S4=2/3: their] household as a couple?

SINGLECODE

Yes	1	
No	2	
Don't know [DS – EXCLUSIVE CODE]	3	
Prefer not to say [DS – EXCLUSIVE CODE]	4	

L THERE IS NO SECTION L.

M Re-contact and close

ASK ALL

M1 Thank you very much for your time, that is now the end of the survey. Would you be willing for us to call you back regarding this study, if we need to clarify any of the information you have given today? You do not have to agree to give us more information if we call you back at this stage, I'm just asking if we might be able to call you to find out if you are able to help. If you agree now but change your mind about receiving a call, you can let us know at any time by contacting a member of the project team.

SINGLECODE

Yes	1	
No	2	

ASK IF M1 = 1

M2 And can we just confirm the best number to contact you on is... [DS: SHOW NUMBER]?

SINGLECODE

Yes	1	
No (WRITE IN CORRECT NUMBER)	2	

READ OUT TO ALL: Thank you for taking part in the survey. If you have any questions or requests about your survey data please contact IFF Research at: REDACTED