

## Annex A: Methodology

### A.1 Research design

This research project consisted of a thorough review of the academic and grey literature, and existing government policy; surveys and a focus group. Further details on each component of the research are provided below.

Through the research we sought to engage with:

- People who have experience of mental health problems and claiming benefits
- Carers who have supported people experiencing mental health problems to claim benefits
- Professionals working with people experiencing mental health problems and claiming benefits

This triangulation of experience allowed us to develop a thorough understanding of the challenges people experiencing mental health problems face in accessing the benefits system.

The research was also shaped by the input of an expert project advisory board, drawing on the knowledge and skills of professionals working in the policy area. Project advisory board members are thanked in the report's acknowledgements.

The benefits system is at a crucial point of change. People are transitioning through natural and managed migration from legacy benefits to Universal Credit (UC). This point of flux, and the 'test and learn' phase of Universal Credit provides a unique opportunity to apply learning from the difficulties people have experienced in accessing legacy benefits to improve the Universal Credit system.

This research project focused on the experiences of people who have claimed benefits in the last two years. While a sizeable proportion of the data collected relates to benefits now consolidated within UC (particularly ESA), similarities in application and assessment processes mean the comparison still offers useful insights for the design and development of UC.

### A.2 Literature review

Researchers completed a thorough review of the existing literature around access to the UK benefits system and the experiences of claimants with mental health problems. This included an initial desk-based review of the existing legal and policy context around legacy benefits and Universal Credit.

Articles for review were identified using a snowball search strategy, searching key journals and databases, using a list of key search terms such as "universal credit", "personal independence payment", "employment support allowance", "mental health", "vulnerable claimant", "common mental disorder" and "serious mental illness".

We used these results as a starting point for our snowball search and used signals such as number of citations and journal reputation as a guide to find further sources. Beyond this, we used more targeted searches to try to fill any apparent evidence gaps. In total, 94 articles were reviewed. A full bibliography is available upon request.

### A.3. Surveys

Four surveys were used to collect data for this project. Three surveys were conducted with Money and Mental Health's Research Community, a group of more than 5000 volunteers with personal experience of living with a mental health problem, or of supporting someone who does. People with lived experience of mental health problems were surveyed twice, through an initial scoping survey and second, detailed survey. We also surveyed members of the Research Community who care for someone with a mental health problem. Finally, members of Money and Mental Health's Professional Network, a group of people working in related fields including advice, mental health and financial services, were surveyed about their experiences.

Where statistics from this survey are quoted in this report, we also provide sample size and a description of the base. Responses to qualitative questions were analysed thematically and used to develop the topic guide for our focus group and illustrate the report.

Further details on each survey are provided below.

#### 1. Scoping survey

Money and Mental Health collected data through a preliminary online scoping survey of our Research Community, between 21 September and 16 October 2018. Surveys were distributed by email, and through the secure online portal to Money and Mental Health's Research Community. To avoid causing unnecessary distress, participants were able to skip questions after initial screening.

362 people with lived experience of mental health problems participated in the scoping survey. This survey provided initial insights into the challenges people faced accessing the benefits system, which were used to inform the design of our detailed survey.

#### 2. Detailed lived experience survey

A further, more detailed online survey was distributed to our Research Community, enquiring about their experiences of accessing the benefits system. Data were collected between 26 October and 16 November 2018. Surveys were distributed by email, and through the secure online portal to Money and Mental Health's Research Community.

Participants were asked about their experiences claiming a wide range of benefits, and also asked if people had ever delayed or decided not to claim a benefit they thought they were eligible for. Subsequent questions screened people for experience of claiming relevant benefits within the last two years. This was to ensure that the data obtained

was relevant in the rapidly changing context of welfare benefits. We also limited quantitative findings to those people who had experience of claiming one or more of the following benefits:

- Employment Support Allowance
- Universal Credit
- Job Seekers Allowance
- Personal Independence Payment
- Housing Benefit
- Council Tax Reduction

Our initial analysis suggested these were the most important benefits claimed by people experiencing mental health problems. Including PIP and Council Tax Reduction allowed us to understand how benefits not administered through UC are working for people with mental health problems, and the challenges associated with navigating separate systems for different claims.

Respondents who did not meet these criteria were excluded from the quantitative results, leaving a sample of 455 people with lived experience of mental health problems who had claimed a relevant benefit in the last two years. Where questions related to experiences claiming a specific benefit, or part of the claiming process, only the responses of those who report claiming that benefit or having experienced that part of the process are included in the base.

A mix of closed and open survey questions asked participants about their experience of accessing the benefits system, including completing initial online and paper-based applications, providing information, attending assessments, ongoing management of claims and challenging decisions. This survey also included a screening question for social anxiety and specific phobia related to the benefits system, which is described further in section A.4.

### 3. Carers survey

A separate survey was sent to people who identified as carers in our Research Community. Here we asked about people's experience of supporting someone with mental health problems with their benefits, and their experience of communicating with benefit agencies. Surveys were distributed between 26 October and 14 November 2019, by email and the secure online portal to Money and Mental Health's Research Community. In total 95 people completed the survey.

Where a Research Community member had both lived and caring experience, their lived experience was prioritised to avoid survey fatigue.

### 4. Professionals survey

A further survey was sent to our Professional Network, seeking the views of professionals who work with people with mental health problems. Here we enquired about the issues professionals came across when supporting people with mental health problems and benefit claims, as well as how people's mental health was affected by the process of claiming benefits. Surveys were distributed by email. We received responses from 73 professionals from a range of backgrounds, from welfare rights and debt advisors to mental health practitioners, between 19 and 26 November.

#### A.4 Tool assessing levels of anxiety when dealing with the benefits system

To understand the impact on our mental health of interactions with the benefits system, we adapted questionnaires developed by the American Psychiatric Association (APA) to assess severity of social anxiety disorder and specific phobias, to instead assess the severity of anxiety that people experience when dealing with the benefits system. We used the same indicators of anxiety as the APA questionnaires, slightly tweaking some statements so as to be relevant to the benefits system. Clinicians conducting DSM-5 field trials found that these tools were a reliable, easy to use, and clinically useful way to assess severity of social anxiety<sup>1</sup> and specific phobias.<sup>2</sup> Our tool should be similarly reliable, as it uses the same model, to assess anxiety in another specific context.

The adapted questionnaire asks respondents how often, if at all, they experienced 10 different signs of anxiety when engaging with the benefits system. Responses are placed on a five-item scale from 0 (never) to 4 (all of the time).

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<sup>1</sup> American Psychiatric Association. Severity Measure for Social Anxiety Disorder (Social Phobia) - Adult. Available from: <https://www.psychiatry.org/psychiatrists/practice/dsm/educational-resources/assessment-measures>.

<sup>2</sup> American Psychiatric Association. Severity Measure for Specific Phobia - Adult. Available from: <https://www.psychiatry.org/psychiatrists/practice/dsm/educational-resources/assessment-measures>.



For each of the statements below, please indicate how often (if at all) you feel/acted this way when dealing with the Department for Work and Pensions, Jobcentre Plus or your local council about your benefits.

	<i>Never (0)</i>	<i>Occasionally (1)</i>	<i>Half of the time (2)</i>	<i>Most of the time (3)</i>	<i>All of the time (4)</i>
<i>Felt moments of sudden terror, fear, or fright</i>					
<i>Felt anxious, worried or nervous</i>					
<i>Had thoughts of being injured, overcome with fear, or other bad things happening</i>					
<i>Felt a racing heart, sweaty, trouble breathing, faint, or shaky</i>					
<i>Felt tense muscles, felt on edge or restless, or had trouble relaxing</i>					
<i>Avoided dealing with the Department for Work and Pensions, Jobcentre Plus or local council about my benefits</i>					
<i>Moved away from the situation or left early, when dealing with the Department for Work and Pensions, Jobcentre Plus or local council about my benefits</i>					
<i>Spent a lot of time preparing for, or procrastinating about (i.e., putting off) dealing with the Department for Work and Pensions, Jobcentre Plus or local council about my benefits</i>					
<i>Distracted myself to avoid thinking about dealing with the Department for Work and Pensions, Jobcentre Plus or local council about my benefits</i>					



<p><i>Needed help to cope with dealing with the Department for Work and Pensions, Jobcentre Plus or local council about my benefits (e.g. alcohol or medications, superstitious objects, help from other people)</i></p>					
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Our interpretation of this screener follows the standard approach of the American Psychiatric Association. From these responses, we calculate a total score for each respondent, from 0 (never experiences any of these signs of anxiety) to 40 (always experiences all of these signs of anxiety). For any respondent who answers at least 7 of the 10 questions, we take an average of their scores, to provide an indication of the severity of phobia that they experience when engaging with the benefits system. This gives a result on a 5-point scale from none (0) to mild (1), moderate (2), severe (3), and extreme (4). Participants who answered fewer than 7 questions are excluded, as this is insufficient information to reliably assess anxiety or phobias.

Average score	Result
$x \leq 1$	None-Mild
$1 < x \leq 2$	Mild-Moderate
$2 < x \leq 3$	Moderate-Severe
$3 < x$	Severe-Extreme

For example, if someone *always* feels anxious and gets a racing heart, when they engage with the benefits system, and *occasionally* avoids dealing with their benefits or spends a lot of time procrastinating, but *never* experiences any of the others symptoms, this would produce an average score of 1, indicating a borderline case of mild phobia when dealing with the benefits system.

Other combinations of responses that would indicate a borderline case of mild phobia:

- *Occasionally* experiencing all of the signs of anxiety when engaging with the benefits system.
- Experiencing half of the signs of anxiety *half of the time*, but *never* experiencing the others.
- Experiencing three signs of anxiety *most of the time*, *occasionally* experiencing one other sign but *never* experiencing the others.

This should not be interpreted as a definitive medical diagnosis, but rather as a useful indication of the severity of distress that people experiencing when dealing with the benefits system. Anyone who is concerned that they might be experiencing anxiety should seek advice from a medical professional.

## A.5 Research Community focus group

A focus group was held on 21 November 2018 to test evidence from the desk-based research and survey and to draw out possible ways to improve access to the benefits system. Participants all self-identified as experiencing mental health problems and having experience of currently claiming benefits, or having claimed within the last two years. There were 7 participants. The focus group was carried out online to maximise accessibility and protect participant anonymity. All focus group participants were offered a £30 Amazon voucher as a thank you gift for taking part.

The focus group considered the following:

- The factors people considered when making an initial claim for benefits
- People's experience of completing benefit application forms
- Whether people were able to explain how their mental health problems impacted on them day to day in applications and at assessment interviews
- People's experience of meeting conditionality requirements and managing ongoing claims
- People's experiences of challenging benefit decisions
- Ways in which each step of the system could be made more accessible to people experiencing mental health problems.

A written transcript of the focus group was thematically coded. Emerging themes were used to formulate an understanding that was checked with other members of the research team, and cross-checked with data from the surveys and the literature.

These findings were used to inform policy recommendations, ensuring our recommendations were grounded in experience and practice.