

FEELLET DOWN'

AN ONLINE FORUM LISTENING EXERCISE REVEALING HOW PEOPLE ARE TALKING ABOUT FINANCIAL HARDSHIP

JAMIE HANCOCK
BILLY HUBAND-THOMPSON
JACK PAY



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ABOUT DEMOS



Demos is a cross-party think tank putting people at the heart of policy-making to create bold ideas and a more collaborative democracy.

This project is part of our work on how to build a more *Collaborative Democracy*, by listening to the voices of those most impacted by policy and using those insights to drive policy improvements. In partnership with the Joseph Rowntree Foundation, we have developed an innovative method of social media listening to shed light on the experiences of people living in financial hardship.

We will also use these insights to inform our work on **Public Service Reform**, by understanding the experiences of those who rely on these services. Our goal is to enable more relational public services, that can empower communities and prevent problems.





Joseph Rowntree Foundation (JRF) is an independent social change organisation, working to support and speed up the transition to a more equitable and just future, free from poverty, where people and planet can flourish.

At JRF we are currently developing an insight infrastructure which, powered by quantitative and qualitative data, will act as a satnav providing a series of possible routes to navigate from problem to solution. Such routes will be paved by data and insights generated through triangulation of data from different sources – established datasets (admin data); new sources (charity data); experimental data products (place-based insight hubs, banking data, consumer data); and lived experience of people (experiential insight, social listening). Data and insights products, which we will generate and disseminate in open collaboration with others, are going to support and sustain a shared movement promoting

innovation, better use of evidence, and data-driven decisions to solve social and economic inequality in the UK.

One of the key aspects of the foundation's insight infrastructure's proposition is to improve our knowledge and understanding of people and communities experiencing hardship, poverty and related issues, in the public and policy debate at a national/regional/local level, on issues they have identified themselves. In this instance, by learning what people share about their experience on social media so to investigate how we can generate and disseminate new and timely insights into the lives of those with direct experience of the issues we care about.

Rosario Piazza, Chief Insight Architect, JRF Aleks Collingwood, Partnership Insight Manager, JRF

ABOUT THE PROJECT

This report is designed to shed light on the experiences of people living in financial hardship through an analysis of discussions in specific online support spaces. It is the first of three installments in 2025, following four waves of this research conducted during 2024. Each wave provides a periodic look at online conversations. Together, they are designed to pick up emerging insights into poverty and hardship over time.

Our analysis draws on posts from selected online forums, where people discuss their experiences of financial hardship and the challenges that they, their friends and their families face. The value of this approach is that it enables us to see what people with lived experience talk about and how they speak without prompting by a researcher. In this way, our methodology offers a direct, unfiltered view into people's day-to-day experiences, hopes and fears. It also allows us

to see how broader social and political events shape what people talk about. Using both quantitative and qualitative analysis, we can get a deeper understanding of life in the UK for some of the most vulnerable people in our society. Meaningful engagement with those with lived experience is an essential part of this work. With this in mind, we have worked closely with the Grassroots Poverty Action Group to shape the focus of our research and to sense-check our findings.

Please see the Appendix for full details about our methodology.

BACKGROUND TO THE PROJECT

In 2023, Demos and the Joseph Rowntree Foundation collaborated on an exploratory pilot project to investigate the following questions:

- What can we learn from social media about people's experiences of poverty and hardship in the UK?
- How can these learnings be scaled or tested in the future?

Following a <u>successful trial</u>, we extended this work into a year long programme consisting of four 'waves'.

Over the course of 2024, we took periodic samples of the online conversation to track how people were talking about their experiences.

- In April 2024 we launched our Wave 1 findings: <u>'This system is rigged'</u>.
- In August 2024, we launched Wave 2: <u>'Fight Like Hell'</u>, with updates to our methodology for gathering social media insights in this area.
- In October 2024, we launched Wave 3: <u>'It Can't Get Any Worse'</u>, which capped off our three-part mini-series focused on fresh perspectives from 2024.

In March 2025, we published "I need help now", a report that looked at trends in online conversations over 14 years of Conservative government.

In this latest report - Wave 1 2025 - we explore trends in online conversations about financial hardship over the start of the new Labour government, following their victory in the July 2025 general election. Our data covers the period from August 2024 - March 2025.

By using this methodology, the report forefronts the voices of people with lived experience of hardship. It also highlights the multiple dimensions hardship can take – financial, social, personal, and physical – which may shape a person's experience.

ACKNOWLEDGEMENTS

This project was funded by and developed in partnership with Joseph Rowntree Foundation.

We are grateful to CASM Technology for their support with technical infrastructure, data collection and methodological guidance, and to the members of JRF's Grassroots Poverty Action Group (GPAG) for their guidance and input.



JRF's Grassroots Poverty Action Group (GPAG) is made up of 14 people with direct experience of poverty from across the UK. Members of the group include people who are most impacted by the cost-of-living crisis, including people from Black and minority ethnic backgrounds, lone parents, Universal Credit claimants, disabled people and unpaid carers – those most at risk of poverty.

The group works on, and supports, a variety of JRF's research and infrastructure projects. Group members bring their experience of living on a low-income but also the skills, knowledge, and experience they may have from employment, voluntary work, caring responsibilities, and community activism.

CONTENTS

| 1 | EXECUTIVE SUMMARY | <u>PAGE 9</u> |
|---|-------------------|----------------|
| 2 | METHODOLOGY | <u>PAGE 13</u> |
| 3 | FINDINGS | <u>PAGE 18</u> |
| 4 | APPENDIX | <u>PAGE 71</u> |



KEY FINDINGS: FINANCIAL HARDSHIP UNDER A NEW LABOUR GOVERNMENT

This report covers August 2024
- March 2025, making it the first
wave of our research that is focused
entirely on dates during a Labour
government.

Throughout the report we have referred to similarities and differences between the findings of this wave of research and last year's <u>Wave 3</u> report, which covered April - August 2024.

Some themes continued to persist from previous waves but took on renewed significance in light of the welfare reforms the government set out in March 2025.

THEME 1

POLITICS AND POLICY CHANGES

- In <u>Wave 3</u>, we found that people were uncertain about what a Labour government would mean for them. In this first wave of 2025, we saw people begin to form their views of the new government.
- Labour's changes to welfare policy emerged as a strong theme in online conversations, particularly in reference to the reforms the government set out in March 2025.

- People emphasised the financial impact welfare reforms could have on their ability to meet key expenses such as food and household bills. They also discussed implications for their physical and mental health, and pressures on their support networks.
- There was also discussion about government and media rhetoric surrounding benefits claimants and disabled people in the context of these reforms

KEY FINDINGS: FAMILIAR THEMES, EVOLVING CHALLENGES

Many of the themes discussed in this report are broadly similar to those covered in previous waves, notwithstanding changes in the prevalence of certain themes and often subtle differences in the ways they are discussed.

THEME 2

BENEFITS

- People voiced uncertainty about how to interact with the DWP's procedures, such as how to claim Universal Credit or how to appeal a rejection decision.
- Claimants shared how interactions with the DWP's staff and services had impacted them negatively – including by making existing health conditions worse.
- Procedures like mandatory reassessments and providing evidence for claims had caused some claimants a great degree of personal strain.

- Our data shows that navigating the benefits system from communicating with the DWP to undergoing assessments

 can be deeply stressful, frustrating, confusing and anxiety-inducing for a lot of people.
- The issues raised are very similar to those we identified in our analysis of discussions between 2010-2024.

KEY FINDINGS: FAMILIAR THEMES, EVOLVING CHALLENGES

Many of the themes discussed in this report are broadly similar to those covered in previous waves, notwithstanding changes in the prevalence of certain themes and often subtle differences in the ways they are discussed.

THEME 3

DISABILITY

- In discussions about disability, reforms to PIP loomed large, with people sharing current challenges associated with assessments and eligibility, as well as fears about the government narrowing PIP criteria.
- Lack of access to social housing was a major concern for a great number of disabled people, many of whom posted online about their worries and sought advice on navigating the system.

- Many disabled people reported struggling with complex housing applications and lengthy waiting lists, and highlighted the negative mental impact of dealing with this.
- Our data also underlined the importance of disabled people's social networks in helping them get the support they need.



METHODOLOGY

We took a similar methodological approach to those applied to previous waves of this work.

In our quantitative analysis, we combined Named Entity Recognition (NER), Surprising Phrase Detection (SPD), Link Analysis, and Semantic Mapping. The latter method enabled us to cluster the data into topics based on semantic similarity i.e. how similar the language used are between different posts. This process enabled us to group these clusters into a hierarchy of themes and subthemes to better understand the overarching trends and discussions. We have visualised the outputs of our quantitative analysis into a series of word clouds, bar charts, and volume over time graphs, which we will be able to compare across the waves to see how conversations have changed over time.

We then utilised qualitative analysis to gain a more fine-grained understanding of how people felt and responded to their experiences relating to three specific topics. Where we have included quotes in order to elevate people's lived experiences, we have been careful to ensure that we preserve their privacy by bowdlerising the quotes. This method ensures that the meaning of the post has been preserved, but the wording or syntax has been changed, so that the author cannot be identified via text matching.

In the report, we make reference to how our findings speak to previous waves of our research. Although we have been consistent in methodological approach, given we have drawn on a different combination of forums to previous research, we must exercise some caution in making direct comparisons between the findings of this wave and those of previous waves.

Please see the Appendix for full details about our methodology.

DIVERSITY, INCLUSION, EQUITY AND JUSTICE (DIEJ) STATEMENT

As part of Demos's ongoing efforts to facilitate greater diversity, inclusion, equity and justice in all areas of our work, we assess and publish our approach to meeting our goals in each of our publications.

At Demos, we put people at the heart of policymaking to make better policies, strengthen citizenry and bring back trust in politics. We need the policymaking process to be more diverse, inclusive, equitable, and just in order to achieve these things.

Our commitment to Diversity, Inclusion, Equity, and Justice (DIEJ) is at the heart of our strategy, and our charitable purpose. Our ambition, in an age of division, is to be "radically inclusive", seeking out the voices that are otherwise left behind.

We embedded DIEJ considerations in to this work by:

- Taking an approach to data collection and analysis that sensitively captures the experiences and challenges of those
 experiencing financial hardship and other forms of disadvantage and marginalisation.
- Ensuring our research was informed by conversations with the Grassroots Poverty Action Group (GPAG), a group of 14
 people with direct experience of poverty across the UK.

DATA COLLECTION - WAVE 1 2025

Wave 1 2025 covers a seven-month period from 20th August 2024 - 19th March 2025. We selected this date range because Wave 4 2024 covered a 14 year period from 2010 – 2024 and did not cover the period from August - November 2024.

We gathered data from 72,629 posts across two forums agreed with JRF, which we narrowed down to relevant subforums. We have referred to these throughout using the pseudonyms FinancialHelp and DisabilityHelp to help protect the anonymity of those posting on these forums. The table below provides further detail on the forums and how we used them:

| FORUM | DESCRIPTION | SUBFORUMS | NUMBER OF POSTS |
|----------------|---|---|--------------------|
| FinancialHelp | A forum focused on providing financial advice and support | 11 subforums relating to personal finances, saving money, benefits, debt, bankruptcy, job seeking, and the intersection of finances and disability. | 24,869 posts |
| DisabilityHelp | A forum dedicated to supporting people with disabilities | 13 subforums relating to living with disabilities, education, care, work for disabled people, disability benefits, finances for disabled people, and housing for disabled people. | 48,762 posts |

COMPARING WAVE 1 OF 2025 WITH PREVIOUS WAVES

This wave focuses on two of the forums previously studied (FinancialHelp* and DisabilityHelp*). It uses a longer time frame compared to Wave 3 of 2024 — seven months rather than three — which enabled us able to analyse a much higher overall volume of posts than in previous waves which focused on three-month periods. Wave 4 of 2024 was exceptional as it analysed 14 years of data to look at the entire period of Conservative government (2010-24) and so does not provide a helpful point of comparison.

| TYPE OF CHANGE | WAVE 3 OF 2024 | WAVE 4 OF 2024 | WAVE 1 OF 2025 |
|----------------|--------------------------------|----------------------------|--|
| Time period | 3 months (April - August 2024) | 14 years (2010-2024) | 7 months (August - March 2025) |
| Data volume | 13,789 posts | 2,821,366 posts | 73,629 posts |
| Forums | 6 forums with 30 subforums | 5 forums with 21 subforums | 2 forums previously studied, with 24 subforums |

*Note: This is a pseudonym. See previous page for full list of subforums.

MOST IMPORTANT PUBLIC FIGURES, ORGANISATIONS AND WEBSITES

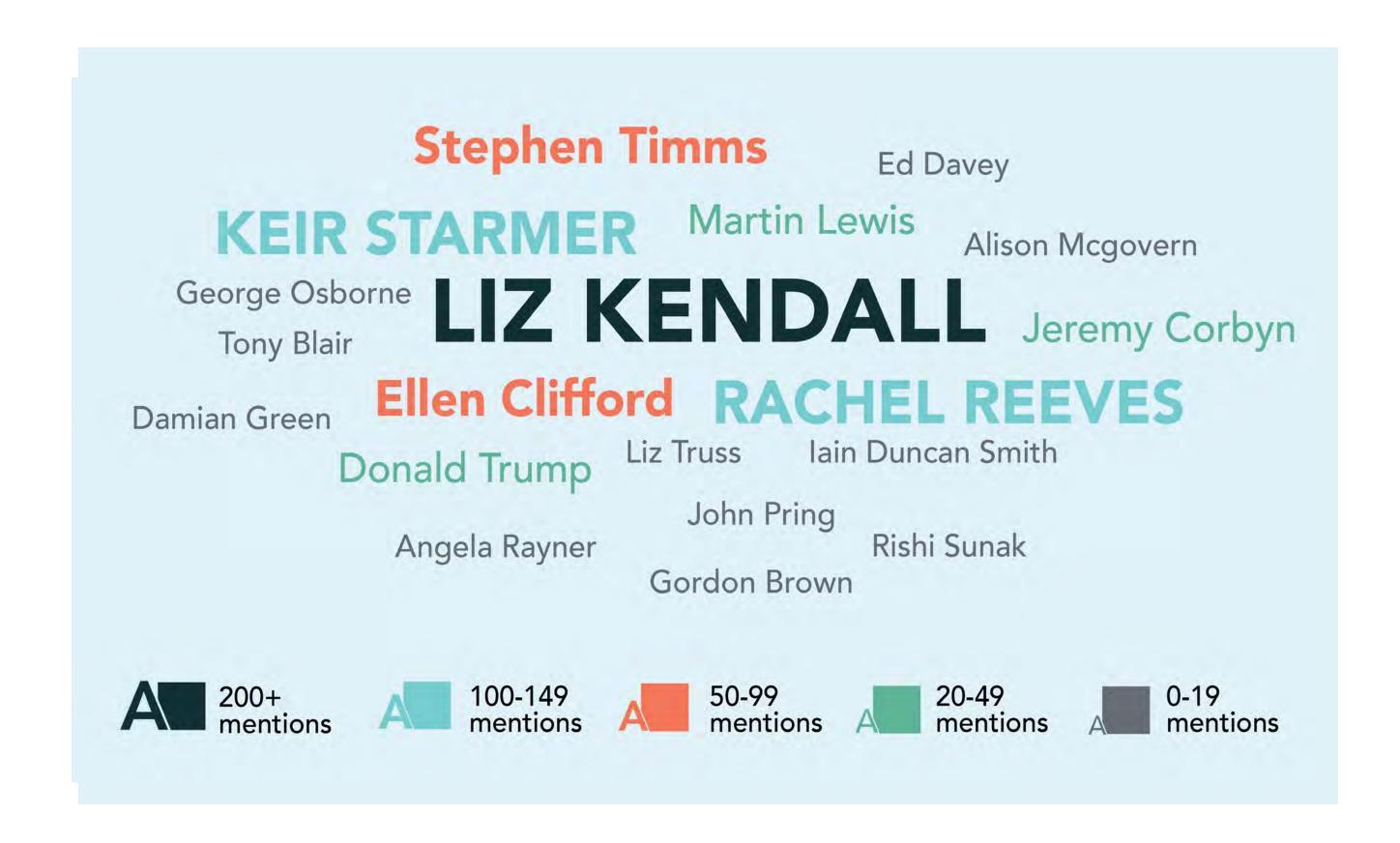
POLITICIANS ARE THE PUBLIC FIGURES MOST ON PEOPLE'S MINDS

Using Named Entity Recognition, we were able to identify where and how often the names of public figures were mentioned. The word-cloud below visualises how frequently each name was mentioned in the data.

Many people posting on these forums were clearly very tuned in to the debate on finances and disability at the political level - the top three people mentioned are all senior government politicians, including **Keir Starmer**.

Liz Kendall, the Secretary of State for Work and Pensions, receives by far the most mentions overall, suggesting that posters are very aware of who she is and interested in her thoughts, actions, announcements etc.

Other prominent figures mentioned included disability rights campaigner **Ellen Clifford** and personal finance expert **Martin Lewis**.



THE DWP EMERGES AS THE MOST IMPORTANT ORGANISATION

The Department for Work and Pensions (DWP) was the most mentioned organisation by far with 2,680 mentions across both forums.

• That is more than 4x the number of the next most discussed organisation.

Other organisations frequently discussed were the **NHS** and **housing associations**.

- We take this to mean that these are the organisations that play the most significant role in posters' lives.
- Google also gets a great number of mentions, suggesting that this is a key way that people seek out the information they need.



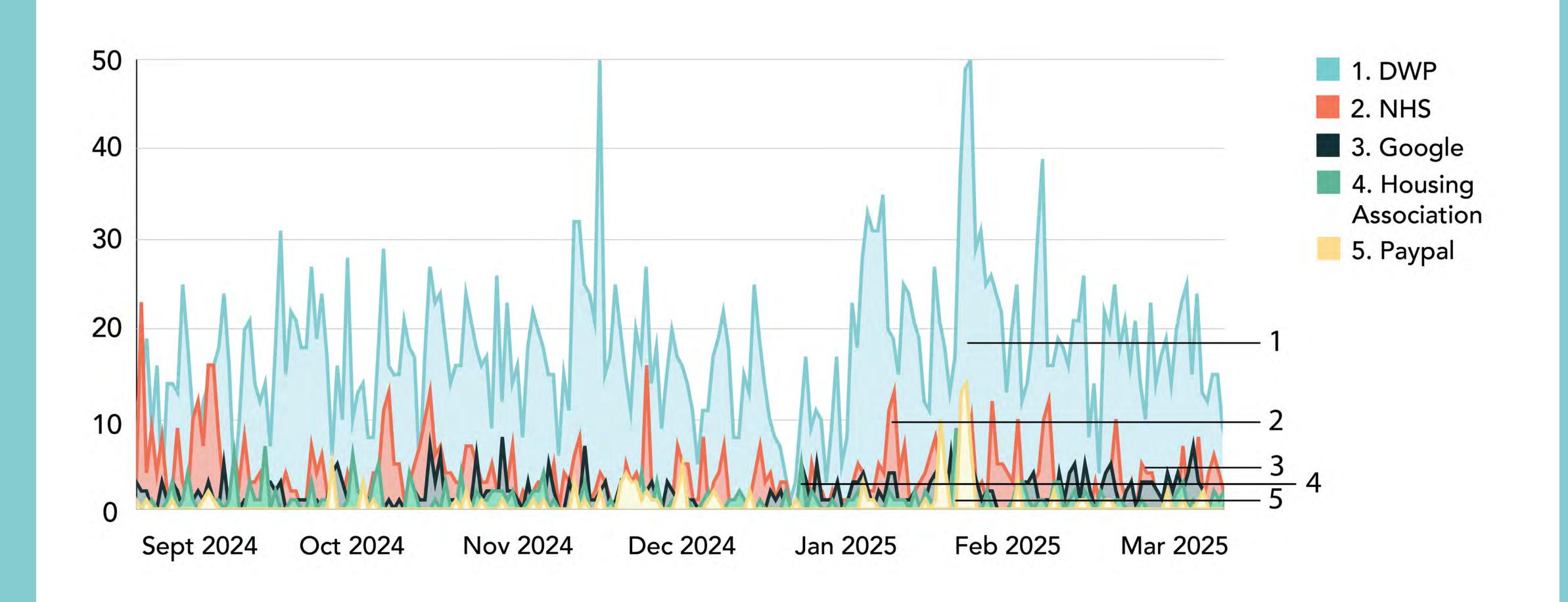
PEOPLE ARE ALIVE TO KEY POLITICAL ANNOUNCEMENTS

The following chart looks at the number of mentions that organisations received on forum posts on a given day. We see clear spikes in the data on particular days. Politician and DWP mentions go up sharply around points that announcements or policy changes are made.

- The chart shows a notable spike in **mentions of the DWP** in late November 2024 and between late January and early February 2025.
- The second spike covers a period in which the government began outline its **plans for benefits reforms** first through media appearances by ministers and later in a formal announcement.
- This spike also aligns with a rise in the number of mentions of **Liz Kendall** (page 81) in mentions of **Personal Independence Payments** (page 84), and in conversations about **welfare policy** news (page 83).



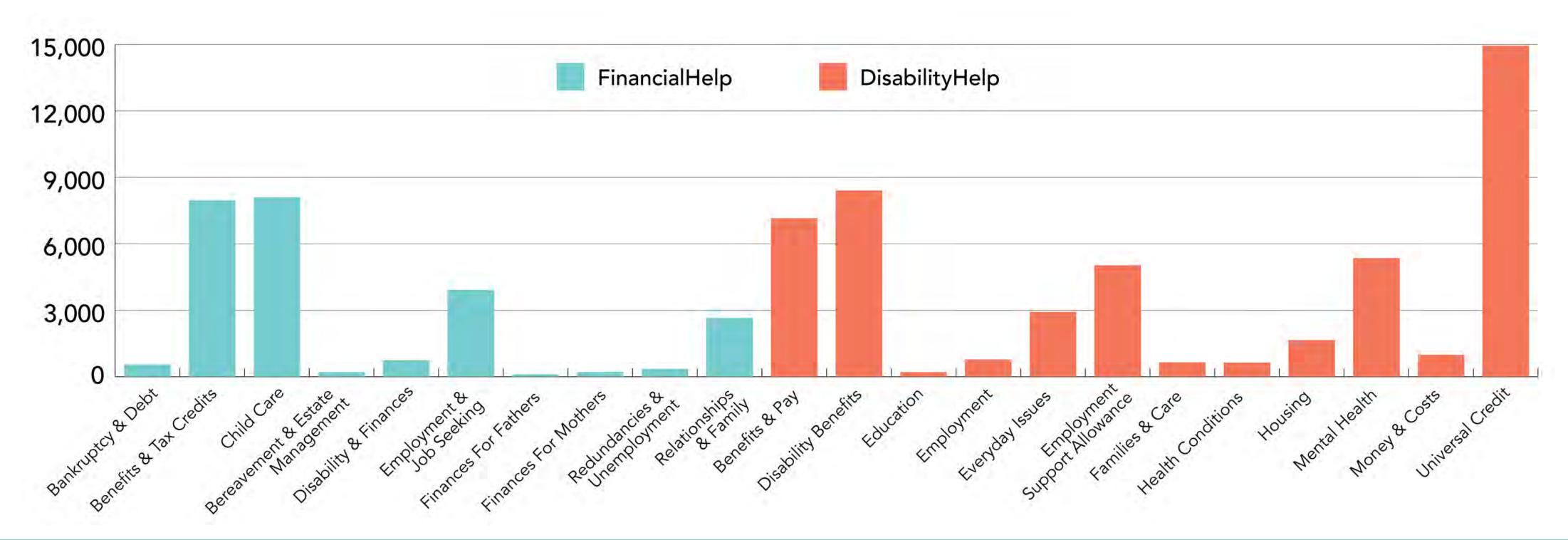
PEOPLE ARE ALIVE TO KEY POLITICAL ANNOUNCEMENTS



OUR POSTS WERE DRAWN FROM A RANGE OF FORUMS

In total, we analysed 73,629 posts from two forums: FinancialHelp and DisabilityHelp. The chart below breaks down how many posts came from each forum and how this was divided across their subforums. All forum and subforum names have been changed to preserve anonymity.

The insights from these different subforums were then used to inform the focus for this study and our subsequent qualitative analysis. More information about this can be found in the Appendix.



FORUM USERS LINKED TO A RANGE OF SOURCES FOR INFORMATION AND SUPPORT

We used link analysis to identify which websites users linked to. The table to the right shows the **top 10 most linked web domains.**

Unsurprisingly, the domains of the forums we analysed came up very frequently. Other prominent websites included the **government's website** (gov.uk) which hosts benefits services and information; **Citizens' Advice** which offers advice on a range of issues; and **AdviceLocal**, which provides information on benefits, work, money, housing problems and other subjects.

We also identified which specific web pages users linked to. The most frequent links were either to advice pages on benefits and the cost of living or to benefits calculators.

| DOMAIN | FREQUENCY |
|----------------------------------|-----------|
| DisabilityHelp | 8628 |
| gov.uk | 1386 |
| citizensadvice.org.uk | 190 |
| FinancialHelp | 182 |
| advicelocal.uk | 162 |
| benefitsandwork.co.uk | 140 |
| assets.publishing.service.gov.uk | 129 |
| entitledto.co.uk | 107 |
| nhs.uk | 84 |
| england.shelter.org.uk | 73 |



OVERVIEW OF THIS SECTION

This section presents our analysis of forum data. It begins by looking at the prominence of different themes in forum posts, before covering three of the most relevant:

THEME 1

POLITICS &
POLICY CHANGE

BENEFITS

THEME 2

THEME 3
DISABILITY

We followed CASM Technology's Semantic Mapping process to group the forum posts into semantically related clusters, and identify a hierarchy of key themes and subthemes common across those clusters.

We start our analysis with the politics and policy change, as:

- i. it provides the unique political and policy context in which this research was conducted.
- ii. discussions about politics and policy interacted significantly with the other key themes we identified.

BENEFITS WERE CONSISTENTLY THE MOST PROMINENT TOPIC OF DISCUSSION

Plotting how frequently the themes appeared over time shows a general pattern of rises and falls in the topic of conversations. On the following page, the graph underscores how 'Benefits' was consistently the theme that received by far the most attention.

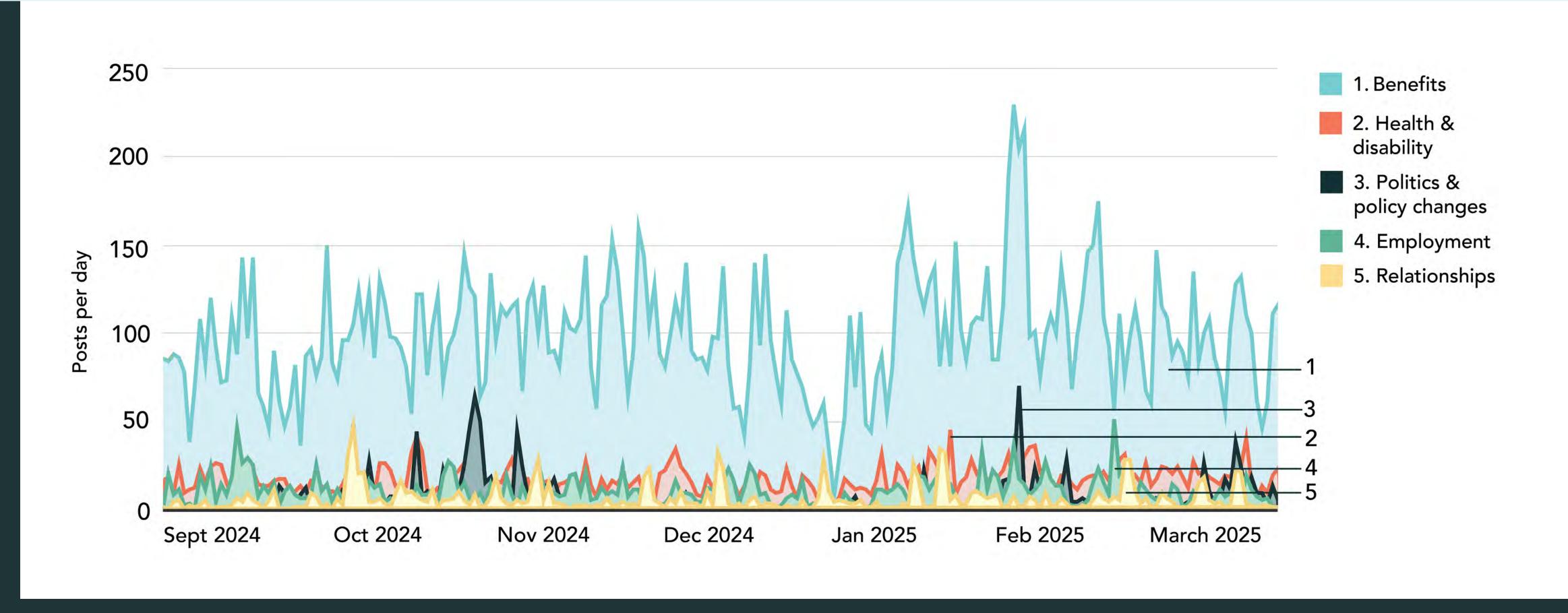
Overall, we identified several strong themes across the forums we analysed. The numbers in brackets show the proportion of relevant posts in our dataset that each theme represents.

Further information about the frequency of key terms and themes and how this varied over time can be found in the Appendix.

- Benefits (28.4%)*
 - Universal Credit (4.8%)
 - Employment Support Allowance (3.6%)
- Disability and chronic health conditions (4.8%)*
- Politics and policy changes (2.1%)*

* the percentage of the analysed data labelled as the given theme

BENEFITS WERE CONSISTENTLY THE MOST PROMINENT TOPIC OF DISCUSSION



1. POLITICS AND POLICY CHANGES

This wave is the first of this project to cover a Labour government. We found many people expressed concerns about the new government's approach to welfare policy. A significant proportion of people's posts centred around the lead up to the Spring Statement (March 2025), which included major changes to Universal Credit and Personal Independence Payment (PIP) eligibility, among other changes. These discussions highlighted the potential of these reforms to impact people's financial, social, and physical wellbeing.

KEY INSIGHTS

- Prior to the Spring Statement (March 2025), people discussed the government's anticipated welfare policy changes and what this could mean for vulnerable people (e.g. in terms of PIP eligibility).
- With speculation about what the welfare 'shake up' might look like, vulnerable people were worried about the future.
- People voiced shock, anger, and great concern about the welfare reforms when they were announced.

- People also spoke about problems with how the government has framed its ambition to get more people into work.
- There was frustration at government and media rhetoric surrounding the drive to get people into work.
- The welfare reforms led many people to draw comparisons with the previous Conservative government.

POLICY CONTEXT: GOVERNMENT WELFARE REFORMS

On 18th March 2025, Liz Kendall (Work and Pensions Secretary) announced a significant shake-up of the welfare system, including narrowed eligibility for personal independence payments (PIP) and freezes in incapacity benefits (representing a real-terms cut), among other changes. This featured heavily in online discussions in the lead-up to the announcements.

Incoming reforms were rumoured for over a month before the official announcement. On 20th January 2025, reports broke that the House of Lords Economic Affairs Committee had called for the government to "accelerate its plans to reform health-related benefits". In the following days, news stories emerged which detailed the government's potential plans, with the Chancellor Rachel Reeves telling newspapers the government would "not hesitate to act" to cut the benefits bill.

The period also saw some ministers telling the media that the number of people on benefits who claimed they could not work was "not good enough" and that some people were "taking the mickey".

Why focus on the lead up to the Spring Statement?

Our analysis focuses particularly on what people said in this period for three reasons:

- 1. The announcements in the Spring Statement were particularly consequential for the welfare system and benefits claimants, including when compared to other announcements such as the Autumn Budget.
- 2. The number of posts on this topic was large enough that it constituted the majority of the discussion on policy changes and therefore merited a specific focus.
- 3. This time period appeared as a distinct peak in the volume of posts almost every time we analysed the trends in what was discussed over time.

IN LATE 2024 AND EARLY 2025, LABOUR'S PROPOSED WELFARE 'SHAKE UP' WAS A KEY TALKING POINT ON FORUMS

Across our data period, a common discussion point was Labour's approach to welfare policy.

Towards the end of 2024 and start of 2025, many people felt uncertainty and concern about what potential reforms might mean for themselves, friends, family, and other vulnerable people.

There was a spike in discussions about the DWP between late January and early February 2025, which coincided with the government beginning to outline its plans for benefits reform. "If all this goes ahead I'm not sure I'll be able to handle it - I am completely unable to work due to my mental state and so if I stop receiving the same benefits as I'm on currently I'm just going to have to eat progressively less, lose my ability to travel, and then just be stuck with worries about my ability to pay my bills and taxes"

"Again, I just see news about welfare cuts everywhere. This would hurt me in a big way - I'm already missing out on PIP payments and so if I get ruled out of WCA due to changes in eligibility I'm simply not going to be able to eat, dress, or look after my kid - I'm incredibly worried"

WITH RUMOURS RIFE AHEAD OF THE ANNOUNCEMENTS, VULNERABLE PEOPLE WERE WORRIED ABOUT WHAT THE WELFARE REFORMS MIGHT LOOK LIKE

With many news outlets running stories concerning potential welfare reforms, many people turned to online forums to seek out further information on issues such as PIP eligibility.

Here, there were concerns about the potential impact of any changes, particularly in the context of cost of living challenges.

Rumour and speculation in the press caused some people a great deal of anguish, with news-related anxiety a common feature of these discussions.

"I really am petrified - everywhere I look there seems to be talk about these welfare reforms - for me, given my disabilities, these changes would be absolutely devastating. This government have been such a disappointment and it's so unfair to keep us waiting like this"

"I've seen loads of dramatic articles talking about the prospect of welfare cuts"

"Alright, anyone able to shed some light on this White Paper? What does it actually mean in terms of PIP and when will any changes happen? I'm pretty scared given the rising cost of bills and other things"

"It's all up in the air - we just have to wait for the government to actually reveal what it wants to do, otherwise it's all just guess work on these forums"

SOME PEOPLE FELT THE LACK OF CLARITY AROUND WELFARE REFORMS WAS A POLITICAL CHOICE

There was some frustration about the government not giving much-needed clarity on forthcoming reforms.

Some posters suggested that the messaging and lack of clarity were tactical political choices. "All this speculation is leading people to panic, with Labour's messaging (and then lack of messaging in some areas!) having real impacts on the mental health of many people"

"I've come to expect this sort of scaremongering from the media but why haven't the government taken steps to provide us with some clarity? They have to understand what this uncertainty is doing to us but do nothing to step in"

"I really just want Liz Kendall to share her reforms all in one go, rather than giving it to us in dribs and drabs leaving the vulnerable in the lurch is terrible"



AS DETAILS WERE REVEALED, PEOPLE VOICED SHOCK, ANGER, AND GREAT CONCERN ABOUT CHANGES TO WELFARE, SUCH AS THE NARROWING OF PIP ELIGIBILITY

In a previous wave of research that included the July 2024 general election, we found that despite many people expressing a desire for the Conservatives to leave office, there was some uncertainty about what a new Labour government would mean, with some expressing "scepticism over Labour's approach to areas such as welfare policy" (see here, page 21).

In this wave, many people said they felt betrayed by the Labour government's approach to welfare policy. This government is just awful. I've been reading about what is coming up - benefits cuts. What are they doing going for the most vulnerable people rather than the rich? They really don't seem to care about us and our ability to get by"

"As someone claiming PIP and LCWRA I'm really worried about what Labour have got planned - benefits cuts would be devastating for me and it feels like we're not able to have our say and push back on this"

THE WELFARE CHANGES LED MANY PEOPLE TO DRAW COMPARISONS WITH THE PREVIOUS GOVERNMENT

Discussions about Labour's welfare policy agenda led many people to make comparisons with the previous Conservative government.

As we covered in our report concerning the last 14 years of Tory-led government, some people had anticipated that Labour might provide favourable welfare support for those facing hardship.

As discussed on the previous slide, we saw many people feeling a sense of disappointment and even betrayal surrounding the direction of the Labour government.

"Please explain why they're punishing the most vulnerable - take LCWRA away and I'll be completely broke.

I thought they might be more left-wing in power but I just can't work them out at all at the moment" "This lot actually appear worse than the previous lot. Will I vote Labour next time around? Absolutely not"

"Feels like they're really out to get us - Kendall's reforms are going to make the Tories look like light touch"

"The Tories and Labour are basically the same - they're removing vital support from us"

"I got the impression they'd be alright before the election but my goodness Reeves and Kendall are showing themselves to be an absolute nightmare"

PEOPLE ALSO SPOKE ABOUT PROBLEMS WITH HOW THE GOVERNMENT HAS FRAMED ITS AMBITION TO GET MORE PEOPLE INTO WORK

In the context of the welfare 'shake up', there were lots of discussions about the government's ambitions to get more people into work.

Some people spoke about how their disabilities meant that it was difficult for them to find and access work while others suggested that they would not be attractive to would-be employers.

Others emphasised the capabilities of those with disabilities, the importance of support in finding appropriate work, and the need for greater investment in making work more accessible.

"When will they get it into their heads that some of us are not able to work and that's not simply a decision we've made? Believe me, I'd love to be healthy and working but I'm just not in a position to work - I'd just be ill the entire time. Good luck finding a workplace and job that can support me with all my conditions. They seem to have no idea what it's like to be in my position"

"Politicians are always talking about getting people into work but they ignore the fact that businesses aren't likely to want to hire people like me, given all my physical health problems"

"Here's the message to politicians - if you want to help disabled people into work, try building and supporting accessible public transport and workplaces - otherwise, you're really jumping the gun by blaming us for not getting into work"

THERE WAS FRUSTRATION AT GOVERNMENT AND MEDIA RHETORIC SURROUNDING WORK AND DISABILITY

More widely, there were frustrations about the government and media's use of language that suggested disabled and other vulnerable people were taking advantage of the state.

"I heard the word 'parasite' used on the TV the other day in relation to disabled people - absolutely terrible"

"There's a real sense of fear among disabled people" - it's not like we've found ourselves disabled out of choice. For all that talk about treating us with respect before the election Starmer has shown himself to be an absolute liar (...) Meanwhile, I keep reading and hearing in the media that we're apparently all taking advantage of the system"

"I'm so tired of the government banging on about 'working people' - I get the awful impression they're missing out those of us who aren't in work and are not worrying themselves with outcomes for disabled people"

2. BENEFITS

Discussions about benefits comprised the largest theme in the data (28.4%) and covered many types of benefits claims. There was a spike in discussions between the end of January and beginning of February 2025.

While this wave is the first of this project to cover a Labour government, people's conversations about benefits on the forums highlighted how challenges we identified in previous waves have continued into the new political era despite hope for change. People discussed various issues including frustrations about the Department for Work and Pensions (DWP)'s processes, waiting times, delays, errors, and a general lack of flexibility. They emphasised how these challenges created further financial difficulty and strained their social support networks. There was an overall sense that the system does not treat benefits claimants with humanity and demands they lose their dignity to receive the help they are entitled to.

Within the benefits theme, we identified several key talking points, including **Universal Credit** (UC), **Employment Support Allowance** (ESA) and other benefits, as well as wider reflections on the benefits system as a whole and interactions with the **DWP**.

In this section, we look at narratives which cut across all benefits discussions and the two most frequently occurring subthemes: Universal Credit and ESA.

2. BENEFITS

KEY INSIGHTS

- Many people were uncertain about how to interact with the DWP's procedures, such as how to claim Universal Credit or how to appeal a rejection decision.
- People often spoke of how interactions with the DWP's staff and services had impacted them negatively – including by making existing health conditions worse.
- Some spoke of how, over time, procedures like mandatory reassments and providing evidence for claims had caused them personal strain.

- Many associated navigating various aspects of the system – from communicating with the DWP to undergoing assessments – with feelings of frustration, confusion, stress, and anxiety.
- The issues raised are very similar to ones we identified in our analysis of discussions from 2010 onwards.

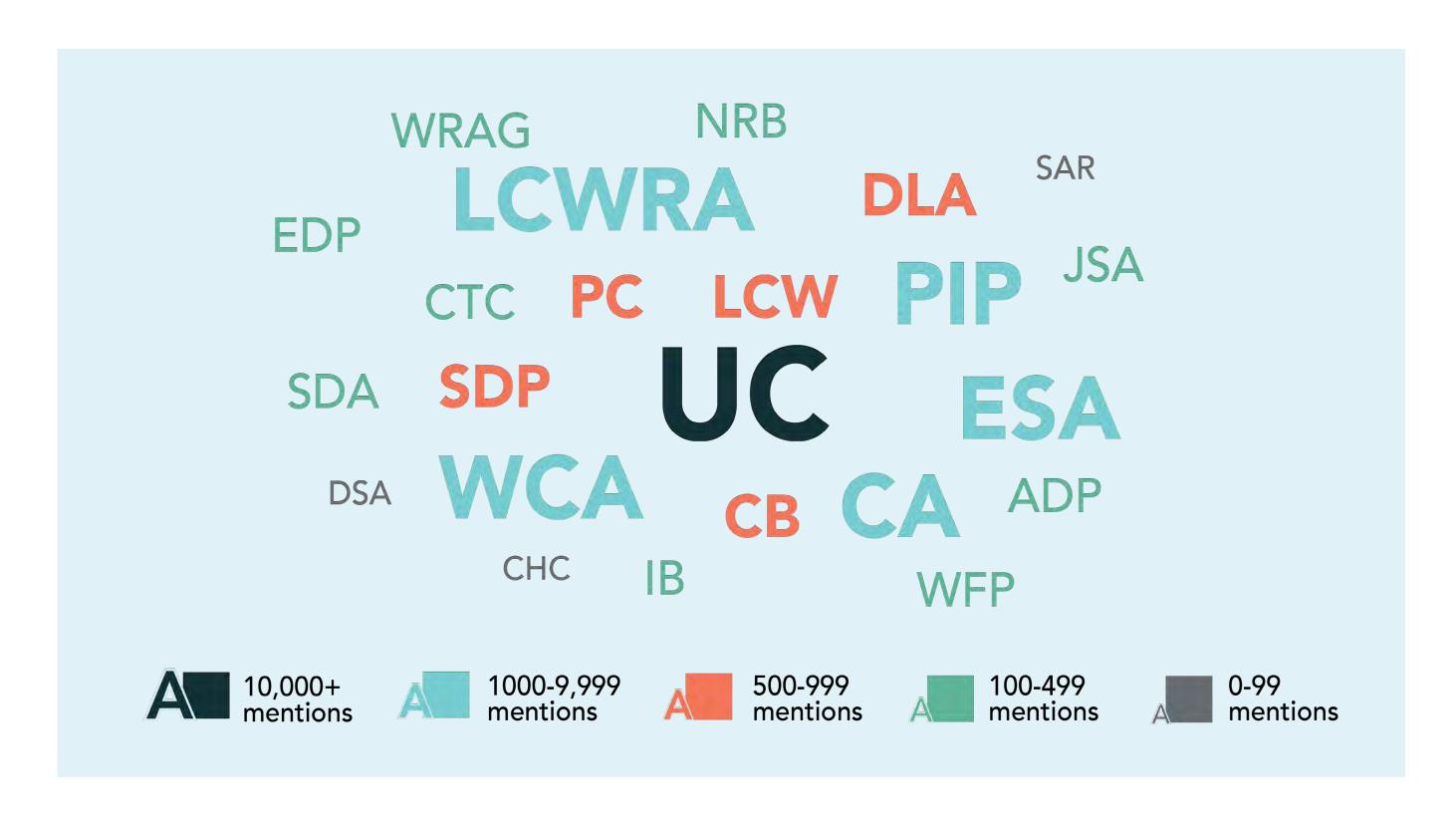
PEOPLE FOCUSED MOST ON UNIVERSAL CREDIT, PERSONAL INDEPENDENCE PAYMENTS (PIP), AND EMPLOYMENT SUPPORT ALLOWANCE (ESA)

Using Named Entity Recognition and keyword matching, we were able to identify where and how often different benefits were mentioned. The word-cloud below visualises how frequently each benefit was mentioned.

Universal Credit was the most discussed benefit (11,177 mentions), reflecting its role as a combination of many types of benefits claims.

Next was **Personal Independence Payments** (6,669 mentions), which is a major disability benefit and the subject of key welfare reforms announced in the Spring Statement.

Third most mentioned was **Employment Support Allowance** (5,453 mentions), which is in the process of being phased out in favour of Universal Credit.



BENEFITS

SUBTHEME 1: DEALING WITH THE DWP

This subtheme covers a range of problems and concerns arising between claimants and the DWP, as the body central to the benefits system overall. These are issues that apply across different benefits. They include:

- Confusion over navigating DWP processes
- A lack of trust in DWP assessments
- Experience of excessive waiting times and delays
- Communication problems in dealings with the DWP
- A lack of empathy and dignity in dealings with the DWP
- Experience of errors made by the DWP
- An overall feeling that dealings with the DWP exacerbated existing health problems

These issues are not new and show significant continuity with <u>earlier waves</u> of this project, including the <u>previous wave</u> which examined conversations from 2010 to 2014. This suggests that problems with the DWP have not improved under the new government.



MANY PEOPLE DISCUSSED CHALLENGES WITH NAVIGATING DWP PROCESSES AND PROCEDURES

People frequently posted about the DWP's processes being difficult to navigate. They explained that it was hard to know if you were doing the right thing or would get your desired outcome. Challenges included:

- Having to explain your circumstances or provide the same information multiple times.
- Having to deal with multiple parties (e.g. DWP and Capita), which could be complex and confusing.
- Not knowing which system to use to provide information to the correct person at the DWP.
- Uncertainty about the status of submissions and assessments.

People's experiences of DWP processes were said to drain their time and make it harder to access help.

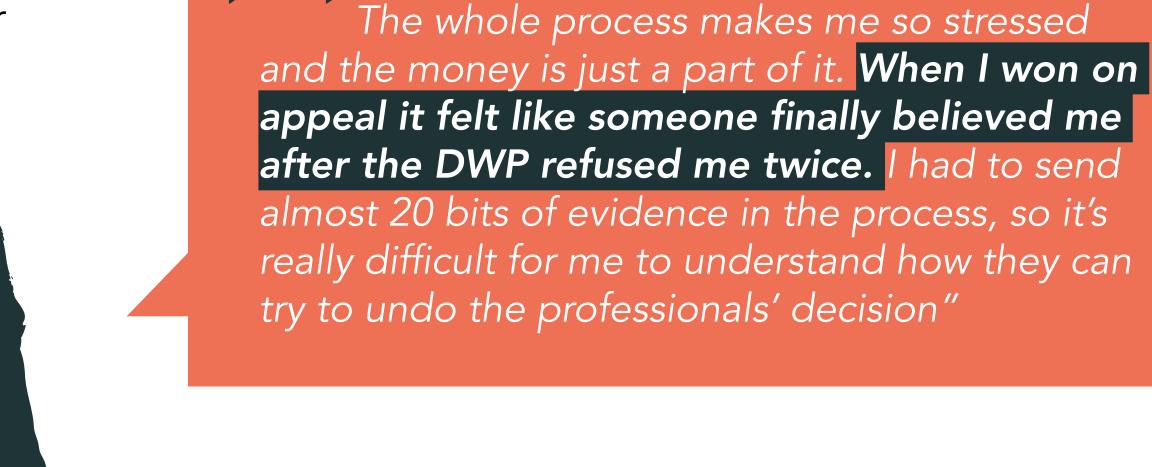
"The DWP seem like they're trying to undermine the judge and doctors in my tribunal case. I've got my MP on my side as well which I hope will help? The process is so stressful"

"I was waiting for the DWP to text me to say they had received my PIP assessment. After one week, nothing - the DWP said they had not received the assessment. They said speak to Capita. But Capita told me the assessment was still "processing". I called almost two weeks later but was told it hadn't gone to the DWP. I waited a week and still nothing. I was then told my assessment was undergoing an audit. It's filled me with dread"

DISCUSSIONS ABOUT ASSESSMENTS REVEALED A DEEP DISTRUST OF THE DWP

As in previous waves, people expressed concern that benefits assessment processes were not fair or accurate. There was a feeling that the DWP would sometimes try to ignore or undermine the judgements provided by professionals such as doctors.

People also discussed a lack of transparency over the decision-making process in the DWP, which further damaged trust in the system when a decision was made against them.



DISCUSSIONS ABOUT ASSESSMENTS REVEALED A DEEP DISTRUST OF THE DWP

When discussing assessments, people often described having to undergo lengthy appeals and complaints processes to correct what they saw as wrong outcomes.

In some cases, people were directed to contact their MP as the easiest way to ensure their concerns about assessments were addressed instead of the DWP's standard complaints procedure.

"I was really angry. I used that energy to get help to make a complaint and to get together more evidence for my mandatory review. This isn't my first assessment rodeo, so from experience I think a complaint is needed. The assessment was not my 'normal' experience – and I've had some truly nasty ones in my time... I'm using the law and making a rebuttal which explains the truth." "I've given them all this information alongside my claim and the DWP has actually agreed that I've had a change in circumstances. It all makes me unsure how they have come to this assessment score... Every day is a struggle for me and I've been given confirmation I can't work because of my mental health. I've requested a mandatory reconsideration"

PEOPLE SHARED HOW EXPERIENCE OF LONG WAITING TIMES AND DELAYS WERE CAUSING REAL HARDSHIP

People frequently mentioned that DWP processes had very long waiting times and delays, with some users warning that the official guidance could significantly underestimate waiting periods.

Some users complained that these waiting times put them in financial hardship and left them without basic essentials.

Waiting times and delays have been a longstanding issue in the benefits system and were highlighted in our previous waves.

These waiting times and delays appeared to have made people feel disheartened, stressed, and resentful towards the DWP. A lack of clear communication seemed to have heightened distrust in the system.

"Lots of people are seeing delays

when they're calculating the amount because the relevant departments are slow at sending the data to Universal Credit"

"I'm just going to get more anxious and depressed if I've got to wait close to a year for the decision on my PIP review"

"I filed a PIP application more than two months ago because I was left unable to leave the house after a road accident. But I'm still waiting to hear something back. It's all just time wasting!"

"After your assessment, the assessment provider will make a report and give it to PIP. Once that's done, it can take anywhere up to twelve weeks for them to make a decision, not eight weeks as they advised you."

MANY ISSUES WITH THE DWP SEEM TO COME DOWN TO POOR COMMUNICATION AND UNPLEASANT INTERACTIONS (1 OF 2)

People expressed concerns and frustrations about their interactions with the DWP, including confusion about how to get in touch with the Department.

People said they had difficulty knowing which were the appropriate communication channels to use when they needed to speak to the DWP or provide information.

Last year I moved to a different kind of ESA. A week ago I had a review and I'm still battered because of it. I don't have anyone around to help me. I just had a phone call from the DWP, who said it was just to make sure I still have capital over £16k. My claim was fine. I've got no idea why they needed to have so much info. Maybe I'm getting paranoid... I'm left wondering when I'll hear back and this traumatising experience will end"



MANY ISSUES WITH THE DWP SEEM TO COME DOWN TO POOR COMMUNICATION AND UNPLEASANT INTERACTIONS (2 OF 2)

Some of those who described actually interacting with the DWP said their experiences were time-consuming and placed an administrative burden on them. Some said that those they spoke to seemed to lack knowledge of the benefits system.

A few people said their interactions were unpleasant, lacked professionalism, and even amounted to being "harassed" in one case.

The DWP has harassed us over this UC situation"

The problem is you haven't actually talked to someone at the DWP. If you ring any of the DWP departments, you'll actually be talking to a call centre. The call centre people don't know much about benefits and are essentially reading from a sheet."

"I've been told today's the last day I have to accept on my journal or I won't get paid. I've added notes pointing out that under the law I don't have to accept, because I'm migrating from a support group with the Severe Disability Premium. It's all unprofessional and extremely stress inducing."



PEOPLE DISCUSSED A LACK OF EMPATHY IN DEALINGS WITH THE DWP THAT FELT DEGRADING

People often presented the benefits system as lacking the flexibility to respond to their real-world circumstances. This contrasted heavily with how the DWP appeared to demand flexibility and patience from benefit claimants.

If claimants made simple mistakes or miscommunicated, these incidents were said to have the potential to trigger major consequences, such as benefits reviews or missed payments. The margin of error given to people was very narrow.

In these descriptions, there emerged a sense that the system did not treat people with humanity and did not allow them to receive benefits with dignity. "I thought my day couldn't get worse. I just received a 2nd letter in the post from the DWP which demands exactly the same things I gave them a month ago. They wanted it delivered by the next day. I've done it, but I'm feeling so unwell."

"My partner and I lost out on over £500 that we need because the DWP is weirdly inflexible about the rules for the assessment period... the system is terrible!"

"To get my PIP review finished last year, I had to get four extensions. That involved having my GP and my MP request a paper-based assessment because it was so mentally distressing... I'm at my wits' end. Being made to explain this all is so embarrassing. It makes me feel less human."

THERE WERE EXAMPLES OF ERRORS MADE BY THE DWP CAUSING FURTHER HARDSHIP AND UNDERMINING TRUST

Some people described instances where the DWP appeared to have made errors, such as miscalculating how much a person was entitled to. These errors were said to have the potential to push people into financial hardship if they led to a claimant receiving less than they were due.

Some errors were said to be due to miscommunication between government departments and flaws in inter-departmental data sharing, which could also result in delays. "From what
I've heard, the
first payment
is incorrect
for far too
many people"

"Today ESA told me they've dropped my claim because I didn't pay the minimum in contributions for 2022 and 2023. But I know I did, because I had the same full time job from for seven years until 2023 which I need to give proof for. It looks like the claim letter isn't correct"

"Look back at the points they gave you for your score and see if that feels like it's fair or accurate. After that, if you think you deserved more points and there was a mistake by the DWP, have a think about making a reassessment request. If you're still unhappy after an MRA, make an appeal."

PEOPLE REPORTED THAT THEIR EXPERIENCES WITH THE DWP HAD EXACERBATED EXISTING HEALTH ISSUES (1 OF 2)

Partly as a result of the issues discussed above, many people posted about how their interactions with the benefits system had made their existing health and wellbeing issues worse.

In particular, people with mental health conditions such as anxiety and depression said the stress the system caused had further undermined their wellbeing.

"I'm in the support group. If I go over to UC, will I have an assessment and will they want me to attend interviews. I've got PTSD. If I get stressed, that causes panic attacks, which trigger my angina. It's going to be so bad if they want to talk or see me in person. I've made a PIP application, but it's been so stressful that I've nearly ended up in hospital several times.

I'm afraid the stress could put me back in hospital."



"I'm just going to get more anxious and depressed if I've got to wait close to a year for the decision on my PIP review"

PEOPLE REPORTED THAT THEIR EXPERIENCES WITH THE DWP HAD EXACERBATED EXISTING HEALTH ISSUES (2 OF 2)

Some people spoke of a vicious cycle, where a person's conditions would lead them to claim benefits and this process would make these same conditions worse.

I'm worried I might need another assessment and I've been reading things about assessments getting altered during audits. My mind and body won't cope with another assessment."

"I've got loads of really difficult mental health issues. Thinking about what will happen now has made me really worried all the time and I'm a mess mentally. I'm scared my LCWRA is going to end. I can't pay for therapy - I need to get better without it. Can someone tell me if PIP can impact LCWRA? I'm anxious they'll stop my LCWRA because I didn't return the form... I'm exhausted"

BENEFITS

SUBTHEME 2: ISSUES WITH UNIVERSAL CREDIT

Universal Credit (UC) was the most frequently mentioned benefit across the forums analysed - covering 4.8% of the dataset. This suggests that questions and concerns about UC are the most numerous. These figures should not be surprising as UC combines multiple benefit claims into one payment – from unemployment and income support to housing assistance.

KEY INSIGHTS

- People's uncertainty about Universal Credit processes and entitlements continued to cause difficulties.
- There were concerns about a perceived increase in Universal Credit reviews, which often felt invasive.



PEOPLE'S UNCERTAINTY ABOUT UC PROCESSES AND ENTITLEMENTS CONTINUED TO CAUSE DIFFICULTIES

People presented the UC system as highly complex – with many types of payment, many variables, and an intricate assessment process.

This was a source of confusion and stress. People often posted to the forums to clarify how to make claims or whether something had gone wrong. The overall result was a sense that the system had become overwhelming: a maze of forms, assessments, meetings, and reviews.

Savings are confusing me now I've got my UC sorted out. I've got a bigger payment than previously which could take me above £6k savings a month. Can someone tell me how it works? Some places say it isn't treated as capital until the assessment is over. Do you tell them how much you have at the end? How do they find out what you've got remaining? I'm so confused!"

"It's baffling that the system seems to penalise you for saving money instead of spending it!"

"My first UC payment statement says that as a single man I'm entitled to £400 a month. I wasn't told at any point during the process that for every point I make, the DWP deduct over half from my tax credit. That leaves me with nothing this month. But... they advised me to work to get that credit. Can someone tell me if I've missed something or if I've gotten it wrong? I needed that tax credit to pay for basics like internet and electricity"

THERE WERE CONCERNS ABOUT A PERCEIVED INCREASE IN UC REVIEWS, WHICH OFTEN FELT INVASIVE

Forum moderators said they had noticed an increase in the number of people being asked to undergo randomised bank reviews to check their UC claims. In our analysis, we also noticed a relatively high number of people saying they had been asked for bank information.

People who were undergoing these reviews tended to describe them as invasive. They were often confused about why they had been selected and worried that they were being accused of wrongdoing. They were also concerned about handing the government data which could be highly personal and sensitive.

I'm scared they'll ask about my PayPal payments too when they rummage through my transactions in the review. I haven't done anything wrong and I haven't got big savings. But this is making me feel like I've done something awful, like I'm already guilty. Some of my credit card transactions on my PayPal are very very personal. It feels like the world hates me..."

"I had one of these bank reviews last year. They look at the transactions to see if the UC payments are correct. It invades your privacy. I was not comfortable at all being asked about my payments and their questions didn't even make sense. They asked about payments for household bills, basic essentials, and a PayPal transaction that only came up

"I'm one of the forum moderators. We've been noticing a large rise in the number of these bank reviews recently. They seem to be chosen at random and they're requesting ID plus four months of bank statements"

BENEFITS

SUBTHEME 3: ISSUES WITH EMPLOYMENT SUPPORT ALLOWANCE (ESA)

Discussions focused on ESA emerged as a prominent subtheme and comprised 3.6% of the overall data.

'Old' ESA is in the process of being phased out, with most recipients 'transitioning' to Universal Credit and/or a 'New Style ESA' (NESA) benefit. Most of the people discussing ESA focused on the process of transitioning from ESA. The specifics of which replacement benefit someone receives – and how much they end up with – appear to vary from person to person. Some people feared being worse off under UC after they cease to receive 'transitional protection' payments intended to make up any shortfall.

KEY INSIGHTS

- Difficulties in migration from ESA to UC were causing some people significant stress.
- Weak communication about the ESA caused great difficulties for some claimants.



DIFFICULTIES IN MIGRATION FROM ESA TO UC WERE CAUSING SOME PEOPLE SIGNIFICANT STRESS (1 OF 2)

Most of the posts on ESA focused on the process of transitioning from ESA to Universal Credit or another benefit (such as 'New Style' ESA).

Much of this discussion focused on the process of UC migration, with fears about people being left worseoff under UC once they stop receiving 'transition protection' payments. These posts reveal the impact that a lack of continuity in benefit income can have on people facing financial hardship. "The transition from ESA to UC has been harrowing. It's just one thing after another. They claim they give you protection but that wasn't the case in my experience"

I've just had my first UC statement after being migrated from ESA. But it looks like I'm getting less than I did on ESA. Can anyone tell me if there's a way to check what transitional protection should come to?"

"Does anyone have any happy stories about transitioning to UC from ESA? All I've seen are horror stories. It's terrifying me."

DIFFICULTIES IN MIGRATION FROM ESA TO UC WERE CAUSING SOME PEOPLE SIGNIFICANT STRESS (2 OF 2)

In a few cases, people described having extremely negative experiences of the transition – including missing payments, new assessment processes, and uncomfortable questioning by the DWP.



"I've got a child who received ESA because she can't work. She got a message from UC saying she had to tell DWP she was receiving UC payments and they should cancel her ESA. But when we phoned the DWP, we were told they knew already and were confused why we were told to ring them. Then my daughter's first statement yesterday was basically what she received before the transition, but with her UC deducted. That meant she lost more than £500, which they said was because she was still claiming ESA. My daughter's very upset"

WEAK COMMUNICATION ABOUT THE ESA CAUSED GREAT DIFFICULTIES FOR SOME CLAIMANTS

There was a tendency for people to mention that the DWP's communications on ESA were unreliable, confusing, or even incorrect at times. There were also concerns about poor communication associated with the transition from ESA to UC.

People spoke of missing letters, inaccurate numbers in official communications, and highly complex language.

"The ESA rates on that letter aren't even the correct current ones – they're the rates for 2019-2020. The letter makes zero sense. I've got no clue why they've sent you that."

I've heard about someone that never received their ESA letter because they had a shared mailbox. They only found out because they called the ESA for a separate reason. The letters can impact someone's benefits and rent severely, so they're very important. Instead of just sending them in normal post, they ought to be sent as signed for or have a notification by phone, text or email."

"You should call them to check. Letters for ESA are well known to be so complicated and hard to understand that even experienced welfare advisors have trouble."

3. DISABILITY AND CHRONIC HEALTH CONDITIONS

As we have found in previous waves of work, **disability and chronic health conditions** were a key feature of online discussions. As covered elsewhere in this report, many conversations centred on navigating the benefits system and discussion of Labour's reforms to welfare policy. People often emphasised how physical challenges can intersect with financial hardship.

In this section, we begin by focusing on conversations surrounding PIP and associated reforms. We then turn to other areas of discussion pertaining to disability and chronic health conditions.

The findings in this section point to the **enduring challenges that disabled people continue to face**, particularly when it comes to issues surrounding housing. Here, there were discussions about issues in housing supply, complex application processes, and concerns about evictions and homelessness. The chapter also contains reflections about the importance of social networks in receiving the appropriate support.

3. DISABILITY AND CHRONIC HEALTH CONDITIONS

KEY INSIGHTS

- In discussions about disability, reforms to PIP loomed large.
- Prior to the 'shake up' announced in March 2025, people were already concerned about PIP assessments and eligibility.
- With PIP eligibility narrowing, people were worried about what this would mean for their finances.
- Housing was also a key discussion point in relation to disability.
- People discussed a lack of available social housing and sought advice to navigate this issue.
- People also discussed navigating complex housing applications and lengthy waiting lists.
- Our analysis also reflected the importance of networks in ensuring disabled people receive the support they need.



BEFORE CHANGES TO PIP ELIGIBILITY WERE ANNOUNCED, PEOPLE DISCUSSED PIP'S IMPORTANCE IN MANAGING FINANCES AND PAYING FOR ADJUSTMENTS

Across our dataset, PIP was the second most mentioned benefit, with **6,669 mentions** in forum posts.

Claimants emphasised PIP's importance for meeting essential costs, such as eating and heating.

They also spoke of the importance of certainty when it came to the amount of money they would be able to claim.

"I'm on Enhanced PIP, have got a condition, and am finding our house really cold at the minute - we don't have heating everywhere in the house. It'd be great if people know of any organisations

that could assist me in sorting this out"

My partner does the cooking for us and I don't want to make things harder for him. We also use PIP to cover other household-related expenses and I'm not sure vouchers would stretch to cover these costs"

"I've got the date of my next statement
- is it possible for me to know how much
money I'll be getting ahead of this date?
I'm used to knowing where I stand when
it comes to my income from work so this
whole thing with getting a higher PIP
rate is new to me"

SOME PEOPLE FELT THEIR PIP AWARDS WERE UNFAIR AND DID NOT REFLECT THE CHALLENGES THEY WERE FACING

People shared their experiences of trying to access PIP awards, often detailing their frustrations at the low assessment scores they had received despite the challenges they face.

These experiences were causing a great deal of worry and distress.

"After my PIP assessment I found I was given a handful of points - I contacted them to check this and provided more evidence but this has got me really worried" I'm pretty miffed by my recent PIP review - I've been given very few points considering the situation I'm in and the challenges I face on a daily basis. My mental health struggles mean I shouldn't be at work and I have had this confirmed to me"

"So I tried to get PIP but my points were really low despite my physical health and various other conditions I've got"

WITH CLAIMANTS ALREADY STRUGGLING, THE PROSPECT OF CHANGES TO PIP ELIGIBILITY CAUSED FURTHER ALARM

Ahead of the government's announced changes to PIP as part of their welfare 'shake up', claimants shared their fears about what a narrowing of eligibility might mean for their finances.

As discussed elsewhere in this report, a lack of clarity about proposed changes to PIP left many people feeling anxious.

At least pensioners are aware of the situation they find themselves in there are so many reforms that affect our community that are completely up in the air, with PIP being one of them tit really is terrible"

"If they go ahead with the changes they're floating it's going to be devastating to the disabled and sick who end up not finding themselves eligible"

"I'm worried that if I can no longer get PIP I might not be able to get my UC transitional protection either - potential cuts are scaring me!"

LACK OF SUITABLE HOUSING FOR DISABLED PEOPLE WAS A KEY ISSUE

In addition to discussions about PIP and associated reforms, people with disabilities (or those posting on behalf of those with disabilities) frequently posted about housing.

Here, there was a lot of emphasis on applications for housing and supported accommodation in particular.

Several discussions centred on the costs (both financial and in terms of wellbeing) of being in inappropriate accommodation.

"I've spent loads of money moving into my new place and it's basically impossible to live in. The council have not acknowledged the issue and with my physical health issues I can't really fix the place up on my own. I'm concerned about what this is doing to my mental wellbeing"

"An occupational therapist should be able to sort you out with a ramp and to sort you a wheelchair - this is what happened with a friend of mine who needed one. I'd definitely pursue this if I were you"

My son has some particular needs and has been left completely in the dark about his potential housing options at the minute he's stuck somewhere completely inappropriate for him and coordinating with social workers and councils is proving pretty impossible. Any ideas on what can be done to make his situation any better?"

HOUSING CONVERSATIONS OFTEN CENTRED ON A LACK OF SUPPLY

People frequently spoke about a lack of housing availability and the implications of having a level of supply that does not meet demand.

Some discussions focused on helping disabled people navigate applications and procedures - encouraging them to act quickly to give them the best odds of securing accommodation that would meet their needs.

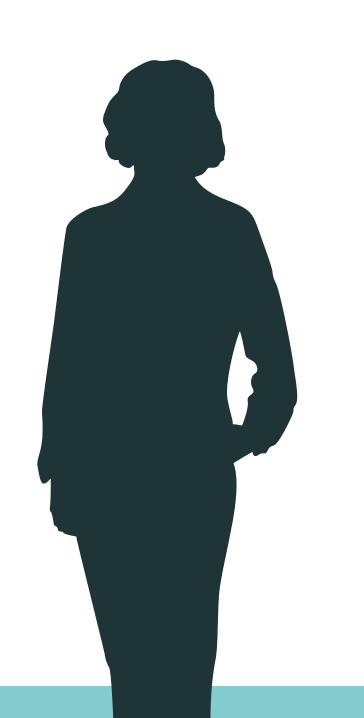
Honestly, I'd get on the social housing list ASAP - you're not going to get what you need without this and it'll likely take while. If you move out optionally at this point you'll be seen as becoming homeless from your own actions so definitely don't do that"

"There's a real lack of bungalows at the moment so councils have to be super considerate about who they offer them to. You could potentially go for ground floor flats but even these are difficult to secure. The other option (though it costs a lot more) is going private"

DISABLED PEOPLE ARE HAVING TO NAVIGATE COMPLEX SYSTEMS AND OFTEN FACE ANXIOUS WAITS FOR HOUSING

People also shared their experiences navigating complex housing systems and processes. Some disabled people spoke about the strain that this was placing on them.

"I've always been in supported accommodation and I'm not sure I'm going to deal with my housing costs. It'd be great to be in sheltered housing if possible as I know people doing this but I'm not sure I'll be eligible"



This whole online bidding for housing thing doesn't make sense for me. I'm really worried about bills as that's previously something that has always been sorted out for me"

"Housing waiting lists will often take an age and there are lots of strict guidelines for bungalows - you need to speak with the council about what you're eligible for and the approach they take"

HOUSING QUALITY WAS ALSO AN IMPORTANT ISSUE FOR DISABLED PEOPLE

People shared their challenging experiences in inadequate housing, both in social housing and in the private rented sector (PRS).

There were also frequent discussions about heating, including heating bills and how to keep warm in cold accommodation. The prevalence of conversations about heating aligns with previous findings in our work covering 2010-2024.

Some people spoke about steps to make their houses more accessible, while others discussed sourcing key household items, with mattresses being a common example.

"When I moved in, the housing association knew I'm a mobility scooter user. Now they're claiming I can't keep it because it's a fire risk due to where it's being stored. The scooter is my legs. The association is saying I need an occupational therapy referral, but I've had one already and they've got the medical report. They're telling me that I'm in breach of the tenancy agreement if I don't have one. I've read the agreement and there's nothing in it in writing that says so. I'm at the end of my tether"

"Can anyone suggest somewhere to get help for things like household white goods, flooring, orthopaedic mattresses, etc.? I'd also like to find some kind of grant, so any that are available if you're not part of a charity group or some be kind of organisation would be helpful. I've been looking with zero luck. I'm struggling with my physical and mental health at the moment, so the combination of looking for items, grants, help on debt and more means I'm falling into a dark place"

"I'd strongly suggest looking at [organisation name]. They can support with heating and some other housing-related things too"

PEOPLE ALSO VOICED CONCERNS ABOUT THE PROSPECT OF EVICTIONS AND HOMELESSNESS

People also voiced concerns about possible evictions and homelessness, asking members for support. Some of these concerns were related to the behaviour of landlords but there were also discussions centred on social housing tenancies.

Those responding would often signpost to relevant charities and other reputable organisations.

"I'm sorry to hear about your situation. Have you spoken to Shelter? They can give advice and help you find the support you need"

Once the landlord has gotten the eviction notice from the court, the council have 56 days to house me. I'm disabled and a vulnerable adult. This feels like a completely outdated way to treat someone like me. I can't just leave"

"I appreciate that you're anxious about what's happening with your housing association. Please try not to let yourself spiral and think of the worst. It sounds like what you're experiencing is a standard procedure. It doesn't necessarily mean there's something wrong with your tenancy. You're a legitimate long-term resident. Housing associations have processes to check tenancies and are not aiming to kick out legitimate tenants"

ONLINE DISCUSSIONS UNDERSCORED THE IMPORTANCE OF SUPPORT NETWORKS FOR DISABLED PEOPLE

Our analysis highlights the importance of networks in ensuring that disabled people can access the support they need.

We frequently saw people posting on behalf of their friends and family, helping them navigate complex systems and processes regarding benefits, housing, and other challenges.

Posts from disabled people themselves underlined the importance of networks in supporting them through challenges they might encounter in their daily lives. "Thanks for replying. I'm trying to source the footrest and adjustments. I'm in the Southwest of England and there's just one shop nearby, which hasn't got anything suitable. I'm trying to find something on the internet but it's hard."

My social worker claimed there isn't a reason for me to have a support worker or carer, even though I've got heart failure, kidney failure, and I'm homebound. I need someone to drive me to appointments. My social worker said my family can take me but my dad is over 70 and my sister works.

Can someone let me know if there's anything I can do to get support?"

"I haven't got a social worker to advocate for me and there isn't anyone that can help me write to someone about my housing and accessibility issues. I need help to write a reasonable adjustments letter for my estate lettings agent. I'm worried though – if I do that, can they kick me out for complaining? I need to know my rights"

CONCLUSIONS

This publication, Wave 1 2025 of our extended Online Forum Listening partnership between Demos and the Joseph Rowntree Foundation, is the first to cover the first months of the new Labour government. In Wave 3 of our 2024 research, we identified a sense of uncertainty among those living in financial hardship about the standing and policy of the new government. In this wave, we have gained insights regarding people's early reflections on the Labour government. Many of these discussions centred on Labour's planned welfare reforms, which became a key talking point on online forums. In these discussions, we heard concerns about both the material impact of such policies (e.g. changes to PIP eligibility) and the wider rhetoric that has accompanied the announcements and their coverage in the media.

Alongside findings pertaining to the new government and its approach to welfare policy, our research speaks to the enduring financial, social, personal and physical challenges faced by people with lived experience of financial hardship. Many of the insights shared in this report, such as complex benefits processes, poor interactions with the DWP, and housing difficulties have endured from previous waves of our research.

Ultimately, our research illustrates the incredibly trying circumstances that some of the most vulnerable people in society live. It illustrates the importance of listening to these people - and putting them at the heart of the policies that affect them.

This is the first of three waves of reporting that will examine how people are talking about financial hardship online across the 2025 calendar year. Our next wave will be published over the summer.

APPENDIX 1 METHODOLOGY

OVERVIEW OF QUANTITATIVE METHODOLOGY (1/3)

Our computational text analysis proceeded through four stages: (1) Named Entity Recognition, (2) Surprising Phrase Detection (SPD), (3) Link analysis, (4) Topic Modelling and Semantic Mapping. The data tables can be found in Appendix 3.

1. Named Entity Recognition (NER)

As in previous waves, we have used the technique Named Entity Recognition to extract names of individuals and organisations from our dataset. NER is a process by which we use a pre-trained algorithm to identify particular entity types within a dataset. In our case, a model trained to identify people and organisations was used. For example, NER seeks to isolate proper nouns from within sentence structures, as these are likely to be of interest.

2. Surprising Phrase Detection (SPD)

SPD is <u>a process</u> which breaks down texts in a dataset into phrases and compares these with a reference dataset in order to identify which phrases are more unusual. It <u>does so by analysing semantic features</u> in each phrase and assigning a score for how likely the phrase was to appear in the reference data.

3. Link analysis

Link analysis is a process which extracts internet hyperlinks and website addresses from text. After extracting these links, we analysed which links appeared most frequently across the forums. Additionally, we analysed which website domains (such as www.gov.uk) appeared most within the links and how often they did so.

OVERVIEW OF QUANTITATIVE METHODOLOGY (2/3)

4. Topic modelling and Semantic Mapping

Semantic Mapping (SeMa) is a part of the Method52 technology and methodology stack designed to aid analysts in performing quantitative and qualitative discourse analysis over a large number of documents. The SeMa process combines a human-in-the-loop strategy with large language model (LLM) based clustering tools, to organise each document into manageable, semantically related sub-collections. As a result, the analyst gain a better understanding of the source material whilst creating a reusable map of discovered themes for future work. SeMa can be broken down into two key phases: 1) a semi-automated clustering and topic analysis, and 2) an analyst driven thematic mapping, detailed below.

Document embedding and clustering

The embedding stage is the process of transforming each document into a numerical representation in a way that captures the document's semantics. Document embeddings can then be compared mathematically, such that documents with similar embeddings share similar meanings. Embeddings are computed using a pre-trained LLM.

For clustering the widely adopted approach of applying UMAP is used to simplify our numerical representations to a lower-dimensional space, suitable for the second step of applying HDBSCAN to identify clusters. We utilise the BERTopic package to encapsulate this process.

OVERVIEW OF QUANTITATIVE METHODOLOGY (3/3)

Thematic mapping

Thematic mapping is the process of a human analyst inspecting samples of documents within each cluster identified in phase one and identifying whether that cluster is relevant to the research, and if so, applying a single theme and subtheme to that cluster. The themes and subthemes used for labelling are generated by the analyst, which will evolve as more of the clusters are understood and experienced. The process of applying labels to the clusters may require one or more iterations over the set of clusters as the analyst's understanding of the data grows. For example, master themes may be combined or split based on shared or disparately related subthemes. Conversely, subthemes may be removed, condensed or influence master themes as the nuances of the conversations in the dataset are better understood.

The aim of this process is to end with a coherent mapping of themes and subthemes to each relevant cluster, that provides a reduction of the clusters into a distinct set of semantic groups.

We then took random samples from the themes and subthemes identified by the thematic mapping, which we used for our qualitative analysis.

OVERVIEW OF QUALITATIVE METHODOLOGY

In order to gain a more fine-grained understanding of our data, we selected the sub-themes based on our prior knowledge and the prominence of the subtheme in the dataset, as indicated by the number of posts labelled with the subtheme. We then generated a random sample of posts from each sub theme. After checking that the posts matched with the relevant sub-theme, we qualitatively coded the data. Overall, we coded 100 posts for each sub-theme (not including posts discarded as they were not matched to the sub-theme in question).

Our analysts created an iterative code sheet of the contents of the posts, tagging each post with any of the relevant codes. The result was an analysis of the significant areas of discussion within each of the sub themes, which showed where particular areas of discussion overlapped.

APPENDIX 2 DEFINITIONS OF ACRONYMS AND INITIALISMS

DEFINITIONS

| DWP | The Department of Work and Pensions |
|------|-------------------------------------|
| HMRC | HM Revenue & Customs |
| NHS | National Health Service |
| CMS | Child Maintenance Service |
| WCA | Work Capability Assessment |
| UC | Universal Credit |
| DLA | Disability Living Allowance |
| LPA | Lasting Power of Attorney |
| ESA | Employment Support Allowance |
| JSA | Jobseeker's Allowance |
| SDP | Severe Disability Premium |
| PIP | Personal Independence Payment |

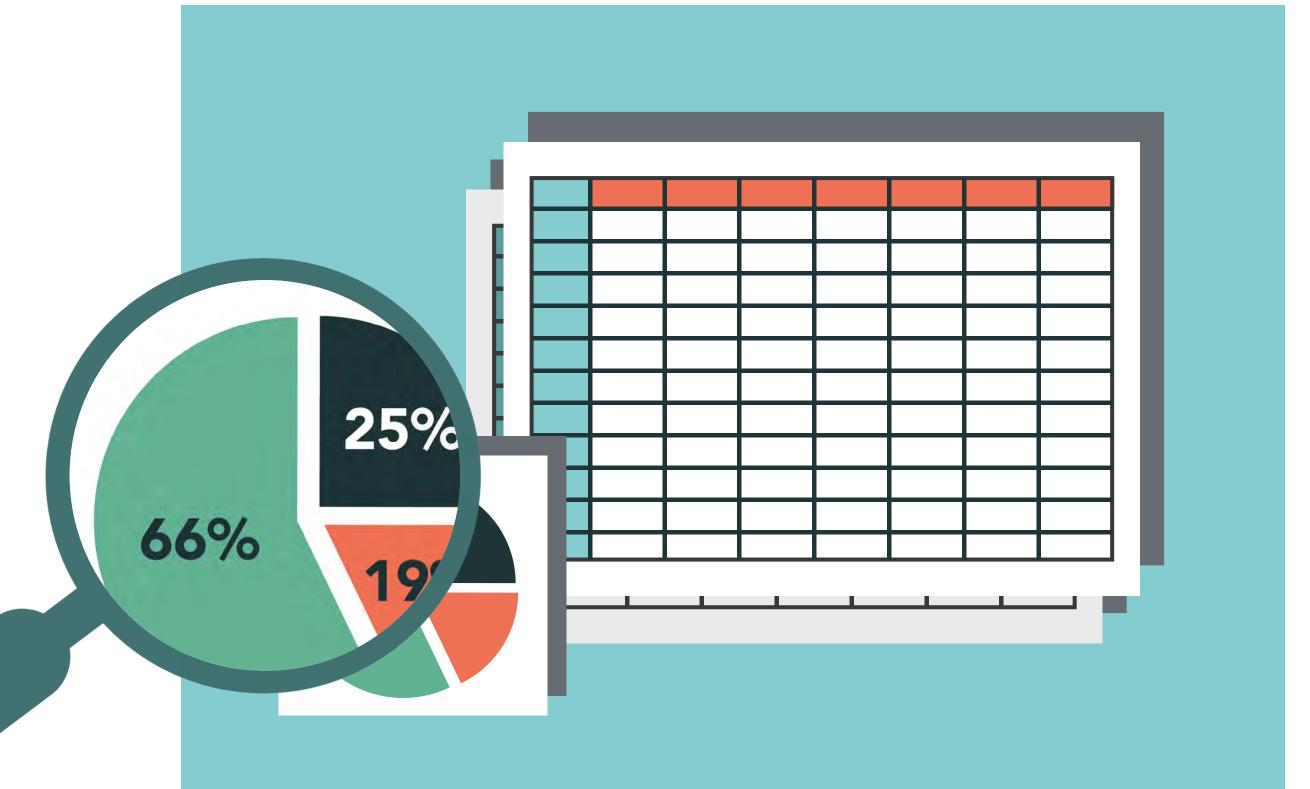
APPENDIX 3 UNDERLYING DATA

ABOUT OUR UNDERLYING DATA

The following slides provider greater detail on the data used for our visualisations and tables. They cover:

Additional volume over time graphs

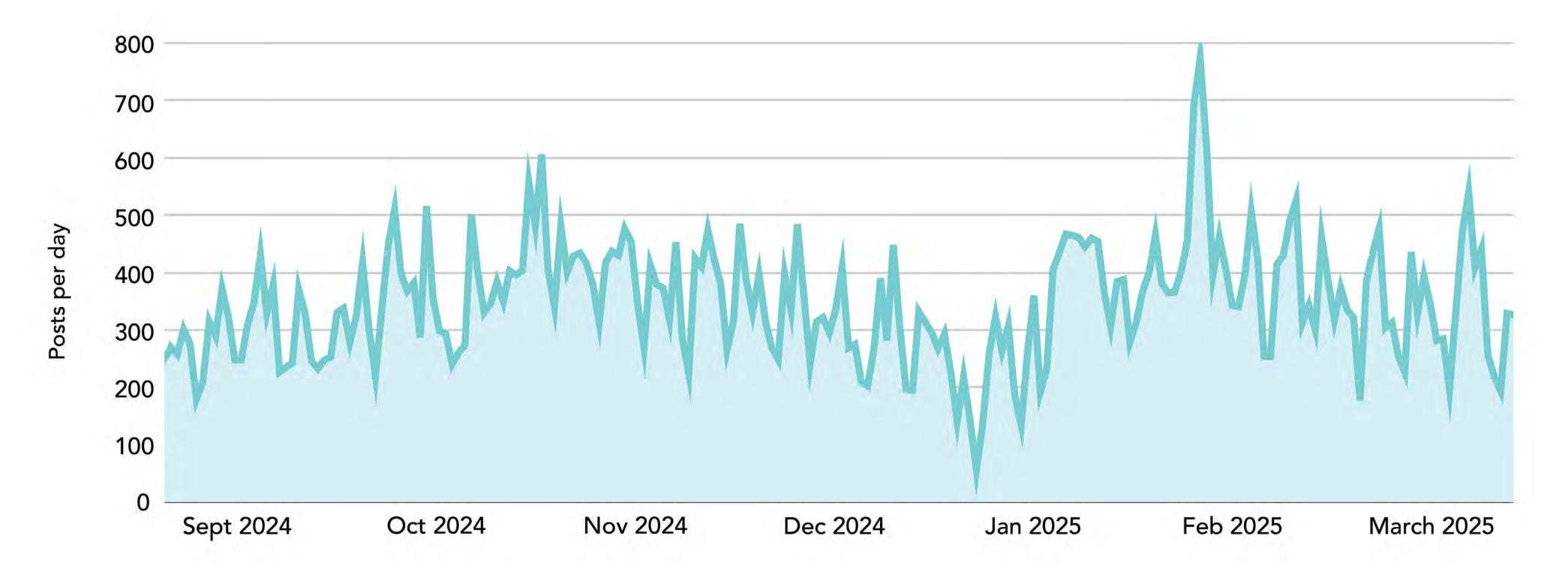
 Extended tables of data on public figures, organisations, links, and phrases used.



VOLUME OF POSTS OVER TIME

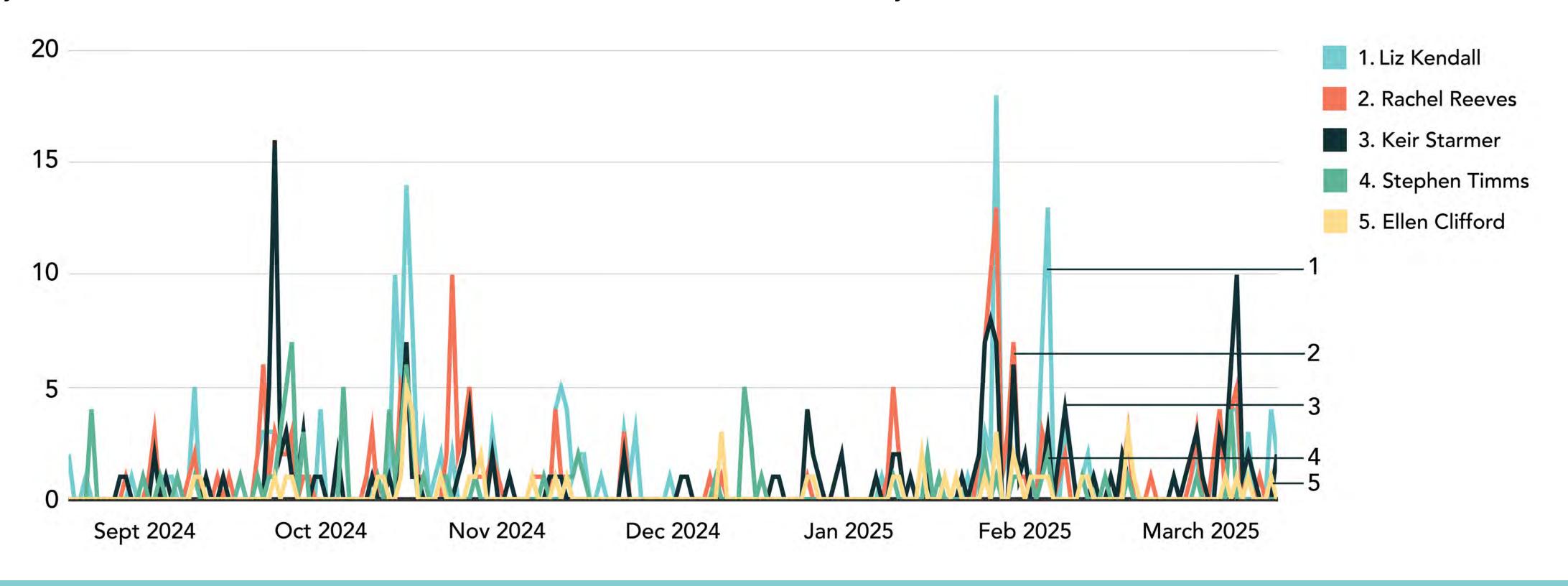
The chart below shows the distribution of posts over time in our dataset (in posts per day).

It shows a notable spike in the volume of posts in the week from January 27th to February 1st 2025. We discuss potential explanations for this increased activity later.



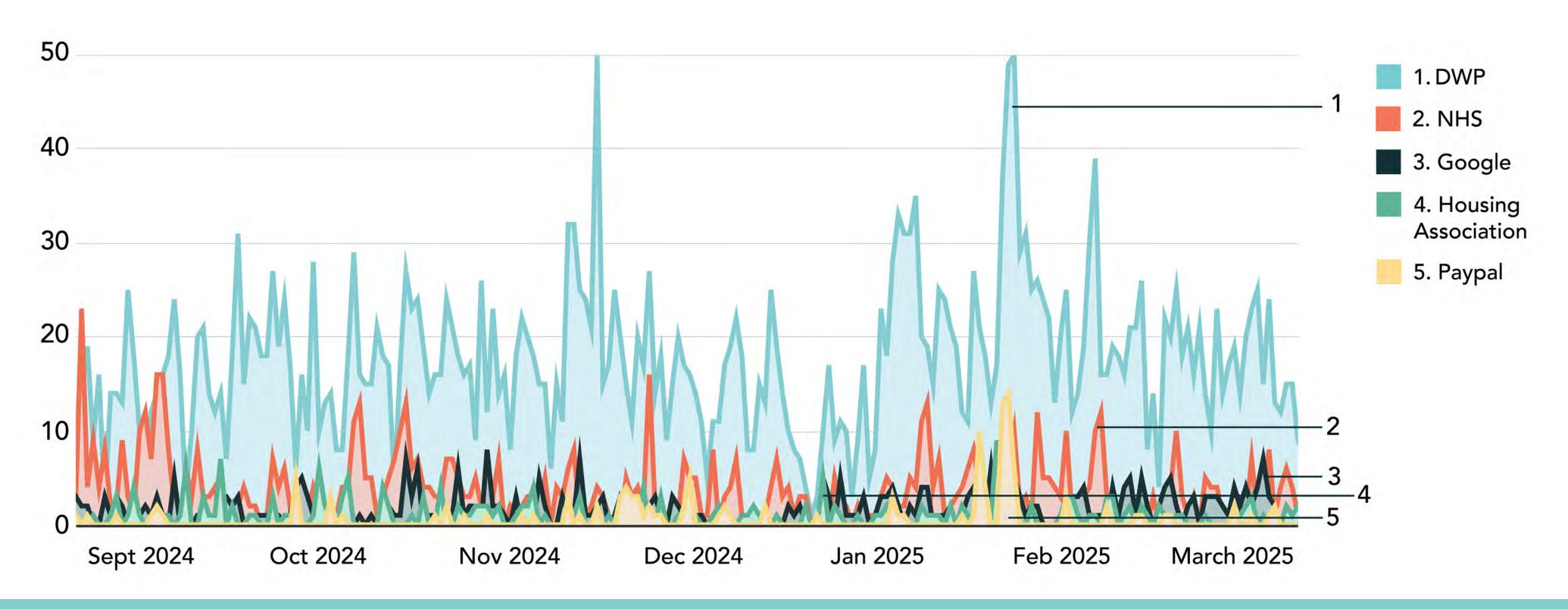
CERTAIN PUBLIC FIGURES WERE FREQUENTLY MENTIONED, PARTICULARLY AROUND KEY POLITICAL MOMENTS

Analysing how public figures were mentioned over time highlights several spikes in discussions around 05/09/24, 18/10/24, 29/01/25 and 07/02/25. These periods align with the lead up to the Autumn Budget (on 30/10/24) and public appearances by Minister Liz Kendall where she hinted at cuts to benefits (late January onwards).



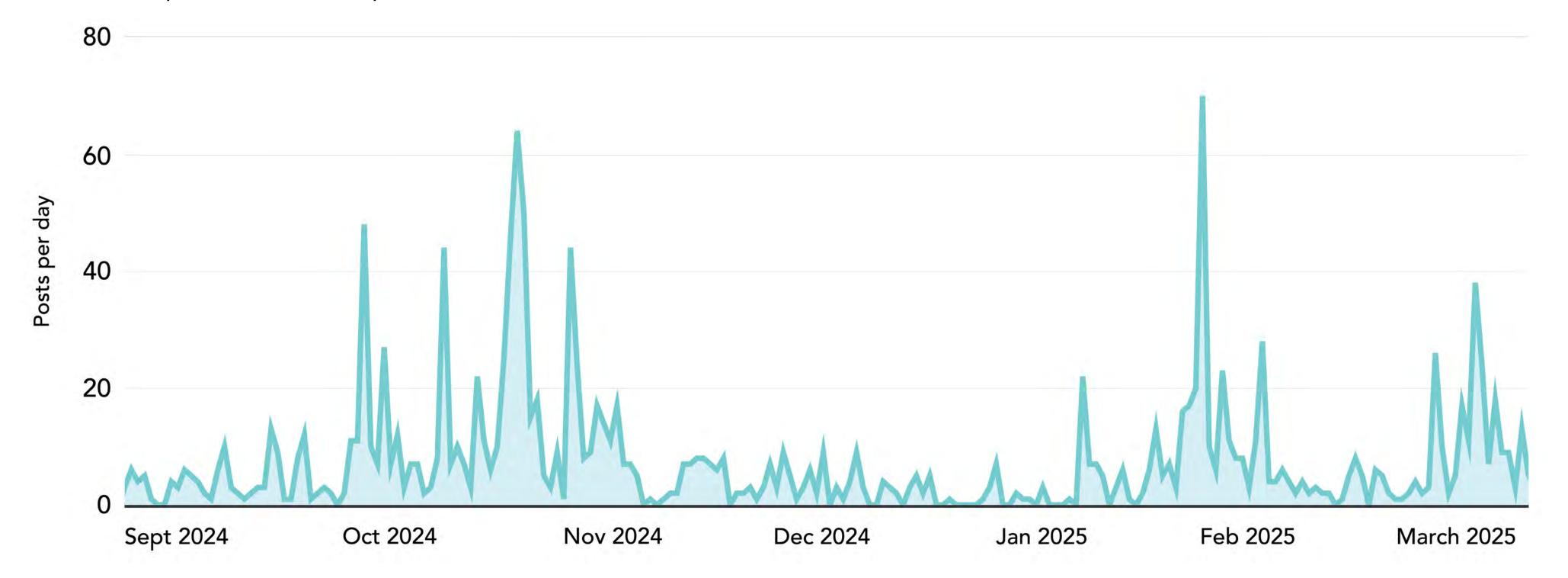
THE DWP WAS THE MOST FREQUENTLY DISCUSSED ORGANISATION

Analysing how organisations were mentioned over time suggests a generally high rate of discussion about the Department for Work and Pensions, with a notable spike in late November 2024 and between late January and early February 2025. The latter time window was the period in which the government began outline its plans for benefits reforms – first through media appearances by ministers and later in a formal announcement. The spike aligns with a rise in the number of mentions of Liz Kendall (page 81), in mentions of Personal Independence Payments (page 84), and in conversations about welfare policy news (page 83).



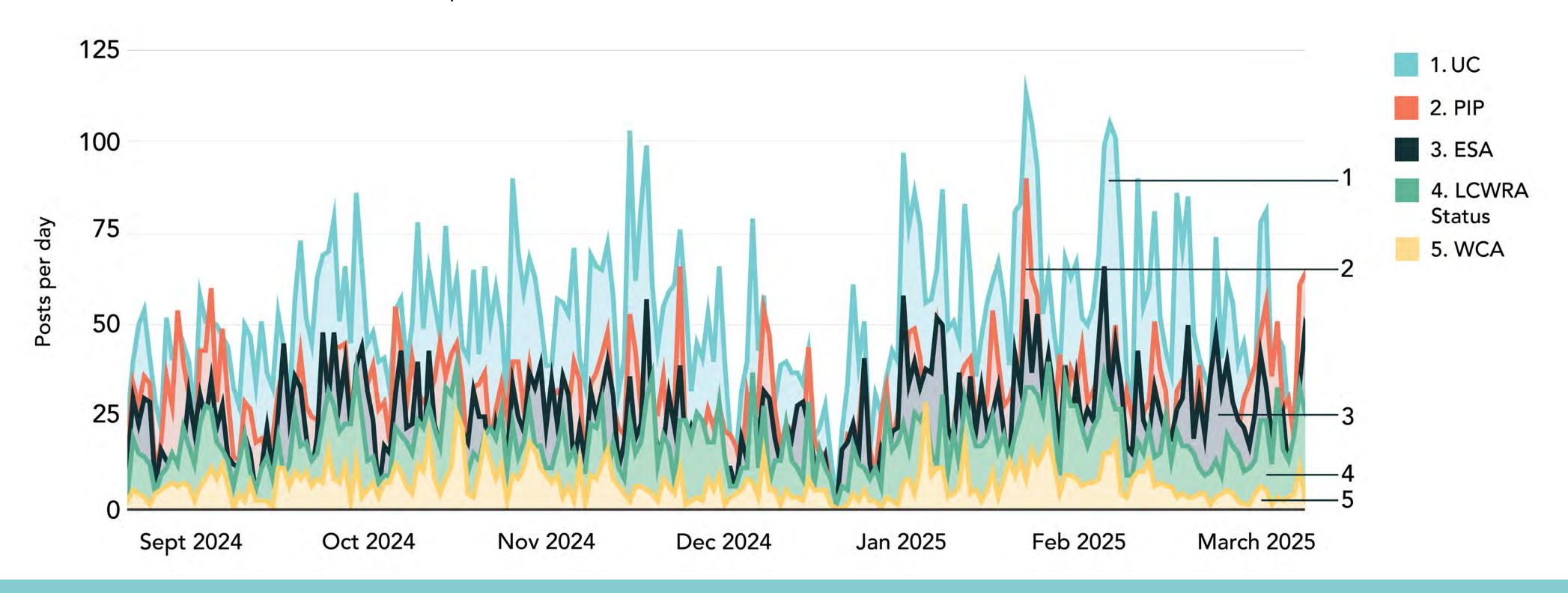
DISCUSSIONS OF POLITICS AND POLICY CHANGES PEAKED LEADING UP TO GOVERNMENT ANNOUNCEMENTS

The number of conversations discussing politics and policy changes spiked in October 2024 and at the end of January 2025. These periods coincide with the lead up to the Autumn Budget announcement and the period when rumours about benefits cuts were circulating in the media. The results suggest that forum users were paying close attention to how government policy could impact the benefits system, their financial wellbeing, and those they cared for.



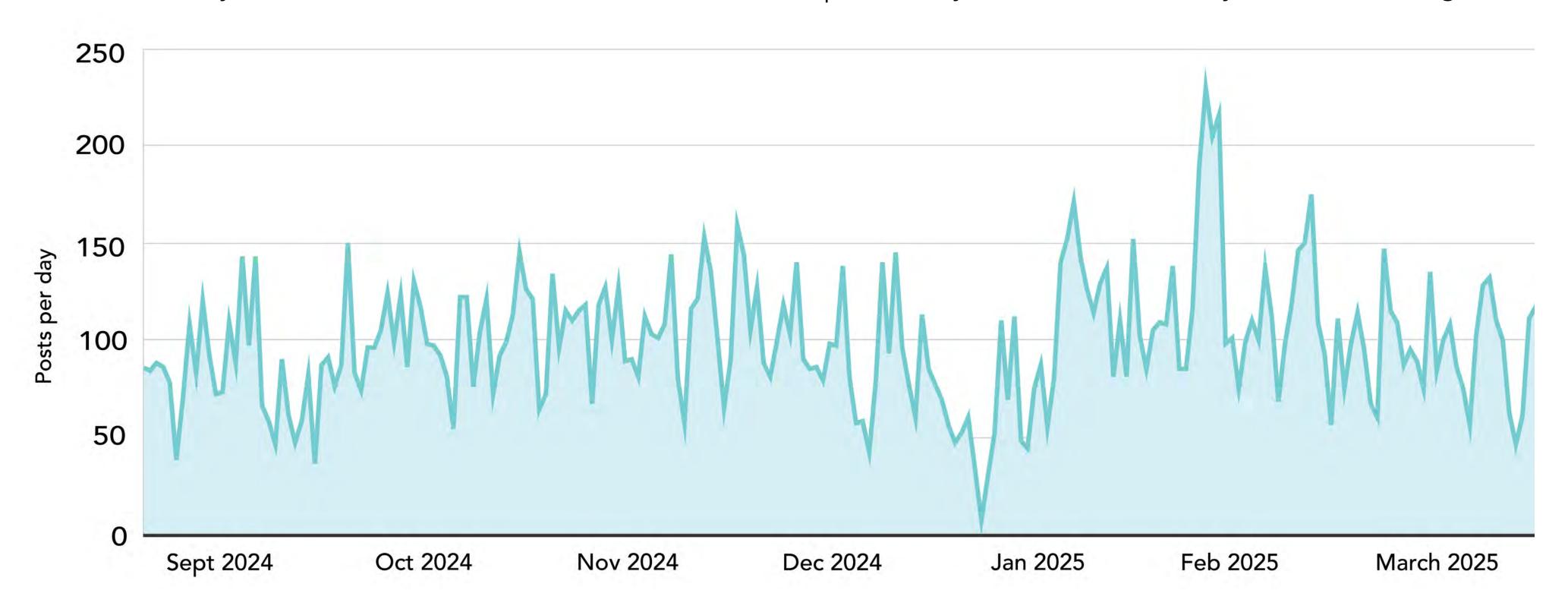
MENTIONS OF BENEFITS WERE CONSISTENT OVER TIME

Plotting how benefits were mentioned over time shows a general pattern of rises and falls in conversations with few outstanding trends. The one exception is a rise in mentions of both Universal Credit and Personal Independence Payments on January 28th. The spike aligns with a rise in the number of mentions of Liz Kendall (page 81) and in conversations about welfare policy news (page 83). It coincides with a period in which several news stories broke which suggested that the government was planning cuts to PIP and UC worth up to £6 billion.



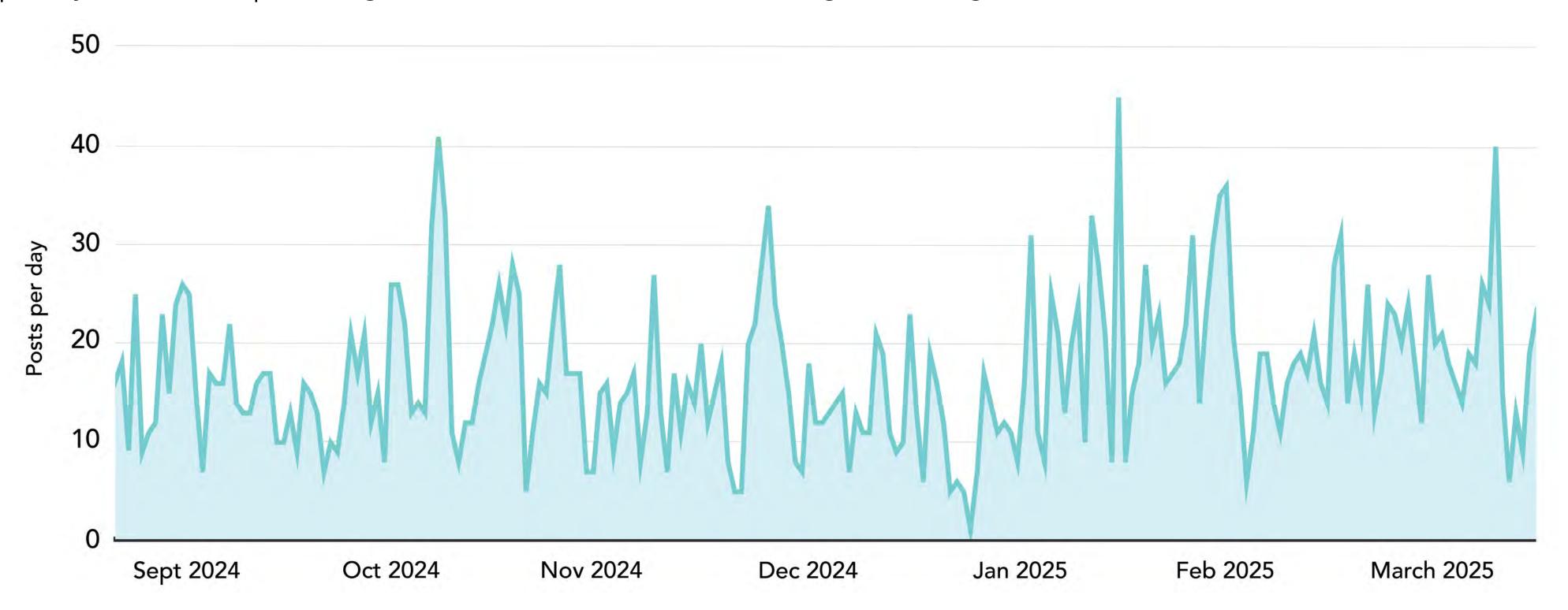
BENEFITS DISCUSSIONS PEAKED JUST BEFORE REFORMS WERE ANNOUNCED

The frequency of conversations discussing benefits was largely consistent throughout the period. It had a noticeable peak at the end of January 2025, in a period which coincides with the time that rumours about benefits cuts were circulating in the media and when government ministers were making statements about benefits claimants. These figures results suggest forum users were relatively focused on benefits issues at all times – and particularly so when uncertainty about cuts hung in the air.



THE FREQUENCY OF DISCUSSIONS ABOUT DISABILITY AND HEALTH WERE CONSISTENT OVER TIME

The volume of conversations discussing disability and health was consistent throughout the period. The highest rise the number of posts came between January 15th-17th 2025. This period coincides with when <u>news</u> broke that the UK's High Court had ruled a government consultation on disability benefits reforms was unlawful. The activist Ellen Clifford – the 5th most frequently mentioned public figure in our data – launched the legal challenge.



PUBLIC FIGURES MENTIONED

| PUBLIC FIGURE | FREQUENCY |
|-----------------|-----------|
| Liz Kendall | 208 |
| Rachel Reeves | 141 |
| Keir Starmer | 130 |
| Stephen Timms | 66 |
| Ellen Clifford | 59 |
| Martin Lewis | 32 |
| Jeremy Corbyn | 27 |
| Donald Trump | 20 |
| Alison Mcgovern | 18 |
| Rishi Sunak | 17 |

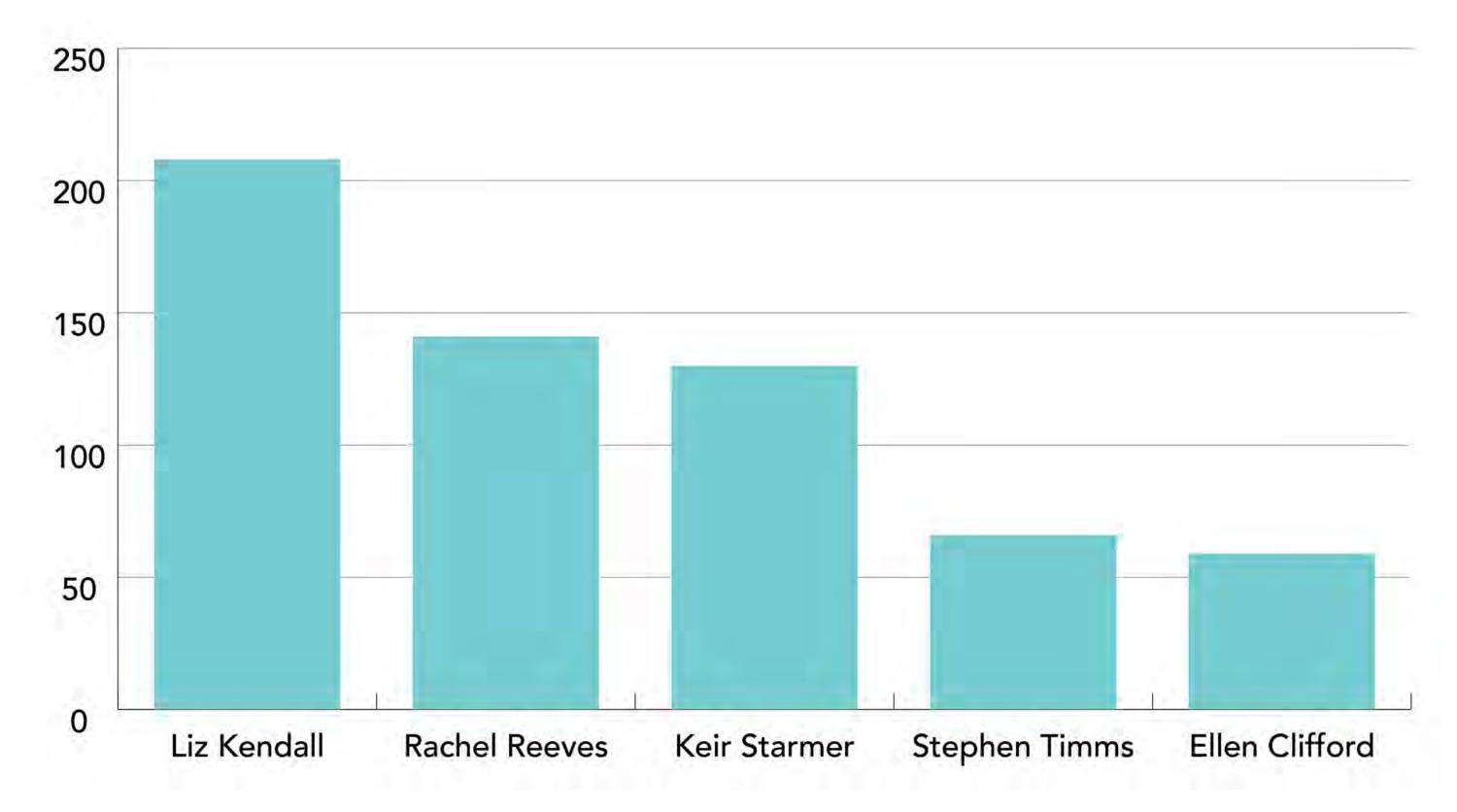


TABLE OF PUBLIC FIGURES EXTRACTED BY NER

| PUBLIC FIGURE | FREQUENCY |
|-----------------|-----------|
| Liz Kendall | 208 |
| Rachel Reeves | 141 |
| Keir Starmer | 130 |
| Stephen Timms | 66 |
| Ellen Clifford | 59 |
| Martin Lewis | 32 |
| Jeremy Corbyn | 27 |
| Donald Trump | 20 |
| Alison Mcgovern | 18 |
| Rishi Sunak | 17 |
| Liz Truss | 13 |
| Angela Rayner | 13 |
| Damian Green | 13 |
| John Pring | 11 |

| PUBLIC FIGURE | FREQUENCY |
|------------------|-----------|
| Ian Ducan Smith | 10 |
| Gordon Brown | 10 |
| Ed Davey | 10 |
| George Osborne | 10 |
| Tony Blair | 9 |
| Vladimir Putin | 8 |
| Wes Streeting | 7 |
| John Mcdonnell | 7 |
| Margret Thatcher | 7 |
| David Cameron | 6 |
| Debbie Abrahams | 6 |
| Paul Gregg | 6 |
| Kemi Badenoch | 5 |
| Jeremy Hunt | 5 |

| PUBLIC FIGURE | FREQUENCY |
|----------------|-----------|
| Dolly Parton | 5 |
| Elon Musk | 5 |
| Thérèse Coffey | 4 |
| John Smith | 4 |
| Louise Murphy | 3 |

ORGANISATIONS MENTIONED

| ORGANISATION | FREQUENCY |
|--------------------------------|-----------|
| Department for Work & Pensions | 2680 |
| NHS | 624 |
| Google | 246 |
| Housing Associations | 97 |
| Paypal | 89 |
| BBC | 74 |
| Facebook | 62 |
| MoneySavingExpert | 59 |
| HMRC | 57 |
| ESA Support Group | 47 |

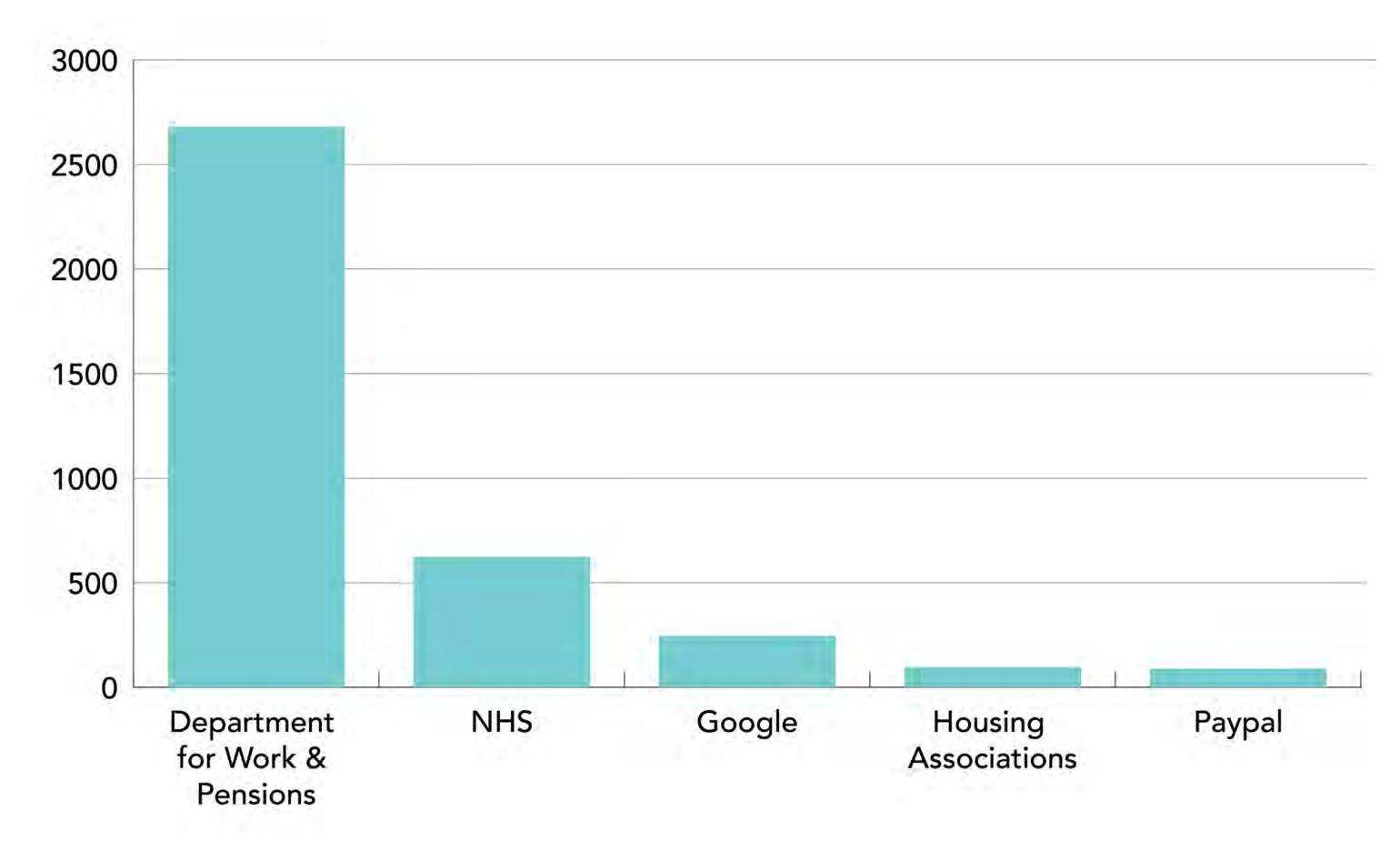


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| NHS | 624 |
| Google | 246 |
| Housing Associations | 97 |
| Paypal | 89 |
| BBC | 74 |
| Facebook | 62 |
| MoneySavingExpert | 59 |
| HMRC | 57 |
| eBay | 47 |
| Barclays | 47 |
| Tesco | 46 |
| United Nations | 44 |
| Labour Party | 44 |

| ORGANISATION | FREQUENCY |
|---------------------------------------|-----------|
| Office of the Public Guardian | 43 |
| YouTube | 42 |
| IFA | 40 |
| INS | 37 |
| Tribunal | 34 |
| MMD | 34 |
| European Union | 34 |
| Amazon | 31 |
| Jobcentre | 28 |
| Health Assessment Advisory Service | 27 |
| HSBC | 26 |
| Lloyds | 24 |
| University | 24 |

| ORGANISATION | FREQUENCY |
|--------------------|-----------|
| IB | 23 |
| Council | 22 |
| SRA | 22 |
| Sainsbury's | 20 |
| The Treasury | 19 |
| Conservative Party | 18 |

BENEFITS DISCUSSED

| BENEFIT | ACRONYM | FREQUENCY |
|---|---------|-----------|
| Universal Credit | UC | 11177 |
| Personal Independence Payment | PIP | 6669 |
| Employment Support Allowance | ESA | 5453 |
| Limited Capability for Work-related activity status | LCWRA | 3830 |
| Work Capability Assessment | WCA | 1441 |
| Carer's Allowance | CA | 1320 |
| Pension Credit | PC | 927 |
| Disabled Living Allowance | DLA | 907 |
| Limited Capability for Work status | LCW | 899 |
| Severe Disability Premium | SDP | 865 |



BENEFITS DISCUSSED

| BENEFIT | ACRONYM | FREQUENCY |
|------------------------------|---------|-----------|
| Child Benefit | СВ | 836 |
| Jobseekers' Allowance | JSA | 361 |
| Nil Rate Band | NRB | 321 |
| Adult Disability Payment | ADP | 233 |
| Work related activity group | WRAG | 204 |
| Severe Disablement | SDA | 153 |
| Allowance | 070 | |
| Child Tax Credit | CTC | 145 |
| Incapacity Benefit | IB | 141 |
| Winter Fuel Payment | WFP | 126 |
| Enhanced Disability Premium | EDP | 124 |
| Continuing Healthcare | CHC | 61 |
| Shared Accommodation Rate | SAR | 51 |
| Disabled Students' Allowance | DSA | 27 |

TABLE OF PHRASES IDENTIFIED BY SPD

| PHRASE | COUNT | SPD SCORE |
|---|-------|-------------|
| Icwra | 5021 | 5.42435586 |
| the dwp | 1718 | 5.081898931 |
| tribunal and the dwp were supposed | 1142 | 4.918867297 |
| Icwra | 5644 | 4.86217179 |
| carers allowance | 1181 | 4.824160566 |
| the dwp | 2436 | 4.760232789 |
| hmrc | 1911 | 4.501332526 |
| carers allowance | 1628 | 4.426315603 |
| the dwp | 718 | 4.277158242 |
| not reflect exactly what your backpay | 1142 | 4.062707948 |
| Icwra | 2348 | 4.033745964 |

| PHRASE | COLINIT | SPD SCORE |
|---|---------|-------------|
| РПКАЗЕ | COUNT | SPD SCORE |
| receive check out entitled to and turn2us | 1142 | 3.978142043 |
| a carer | 340 | 3.896058494 |
| hmrc | 2130 | 3.891010808 |
| the wca | 319 | 3.827662267 |
| the executors | 336 | 3.780203725 |
| carers allowance | 447 | 3.739699064 |
| thankyou | 904 | 3.709891522 |
| during covid closed your claim afterwards | 1142 | 3.668167189 |
| a carer | 504 | 3.631184147 |
| dla | 830 | 3.624497723 |
| doesn | 1 | 3.535783887 |
| lcw | 697 | 3.44988042 |

| PHRASE | COUNT | SPD SCORE |
|--|-------|-------------|
| lcw lcwra uc guide to | 291 | 3.417659191 |
| backdated | 651 | 3.381614788 |
| Icwra | 623 | 3.377470639 |
| to hmcts benefit appeals live chat | 1142 | 3.359205738 |
| participate thinking of cancelling your claim | 1142 | 3.356694436 |
| hmrc | 1169 | 3.340641371 |
| receive check out entitledto and turn2us | 1142 | 3.33208773 |
| with mandatory reconsiderations our main post | 1142 | 3.319118501 |

TABLE OF WEBSITE DOMAINS FROM LINK ANALYSIS

| DOMAIN | FREQUENCY |
|--------------------------------------|-----------|
| DisabilityHelp | 8628 |
| gov.uk | 1386 |
| citizensadvice.org.uk | 190 |
| FinancialHelp | 182 |
| advicelocal.uk | 162 |
| benefitsandwork.co.uk | 140 |
| assets.publishing.service. gov.uk | 129 |
| entitledto.co.uk | 107 |
| nhs.uk | 84 |
| england.shelter.org.uk | 73 |
| turn2us.org.uk | 65 |
| legislation.gov.uk | 59 |
| scope.org.uk | 48 |
| disabilitynewsservice.com | 42 |

| DOMAIN | FREQUENCY |
|----------------------------------|-----------|
| theguardian.com | 39 |
| grants-search.turn2us.org. uk | 37 |
| disability-grants.org | 34 |
| ageuk.org.uk | 30 |
| disabilityrightsuk.org | 30 |
| lha-direct.voa.gov.uk | 28 |
| makeacomplaint.dwp.gov. uk | 26 |
| data.parliament.uk | 25 |
| bigissue.com | 23 |
| moneysavingexpert.com | 22 |
| bbc.co.uk | 22 |
| rightsnet.org.uk | 22 |
| moneyhelper.org.uk | 20 |
| whatdotheyknow.com | 20 |

| DOMAIN | FREQUENCY |
|--|-----------|
| motability.co.uk | 20 |
| youtube.com | 17 |
| litrg.org.uk | 17 |
| acas.org.uk | 17 |
| youtu.be | 17 |
| ipsea.org.uk | 17 |
| step.org | 16 |
| thecanary.co | 16 |
| benefits-calculator.turn2us. org.uk | 15 |
| community.hmrc.gov.uk | 14 |
| independent.co.uk | 14 |
| nhsbsa.nhs.uk | 14 |
| google.com | 13 |
| parliament.uk | 13 |

TABLE OF SPECIFIC WEB PAGES FROM LINK ANALYSIS

| URL | FREQUENCY |
|--|-----------|
| https://advicelocal.uk/welfare-benefits | 146 |
| https://www.gov.uk/benefits-calculators | 71 |
| https://www.benefitsandwork.co.uk/universal- credit-uc/uc-faq/limited-capability-for-work- related-activity | 55 |
| www.gov.uk | 49 |
| https://www.entitledto.co.uk/benefits-calculator/ | 40 |
| https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/pip-assessment-guide-part-2-the-assessment-criteria#daily-living-activities | |
| https://www.citizensadvice.org.uk/benefits/ universal-credit/claiming/contact-us-about- universal-credit/ | 38 |

| URL | FREQUENCY |
|---|-----------|
| https://www.gov.uk/cost-living-help-local-council | 37 |
| https://grants-search.turn2us.org.uk/ | 37 |
| https://www.nhs.uk/conditions/social-care- and-support-guide/help-from-social-services- and-charities/getting-a-needs-assessment/ | 34 |
| https://www.gov.uk/guidance/new-style- employment-and-support-allowance | 31 |
| https://www.disability-grants.org/grants-for-household-items.html | 30 |
| https://makeacomplaint.dwp.gov.uk/ | 26 |
| https://www.gov.uk/guidance/find-your-health-assessment-provider | 25 |
| https://www.gov.uk/pension-credit-calculator | 21 |
| https://lha-direct.voa.gov.uk/ | 19 |

TABLE OF SPECIFIC WEB PAGES FROM LINK ANALYSIS

| URL | FREQUENCY |
|--|-----------|
| https://www.citizensadvice.org.uk/about-us/contact-us/contact-us/help-to-claim/ | 18 |
| https://www.entitledto.co.uk/ | 17 |
| https://www.entitledto.co.uk/help/ employment-and-support-allowance- contribution-based | 16 |
| https://forum.scope.org.uk/ discussion/125931/universal-credit-bank- reviews-frequently-asked-questions | 15 |
| https://www.gov.uk/inherits-someone-dies-without-will | 15 |
| https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/pip-assessment-guide-part-2-the-assessment-criteria | 15 |
| https://advicelocal.uk/ | 15 |

| URL | FREQUENCY |
|---|-----------|
| https://www.ipsea.org.uk | 15 |
| https://benefits-calculator.turn2us.org.uk/ | 14 |

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DEMOS

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At a crossroads in Britain's history, we need ideas for renewal, reconnection and the restoration of hope. Challenges from populism to climate change remain unsolved, and a technological revolution dawns, but the centre of politics has been intellectually paralysed. Demos will change that. We can counter the impossible promises of the political extremes, and challenge despair – by bringing to life an aspirational narrative about the future of Britain that is rooted in the hopes and ambitions of people from across our country.

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15 WHITEHALL, LONDON, SW1A 2DD
T: 020 3878 3955
HELLO@DEMOS.CO.UK
WWW.DEMOS.CO.UK