WELFARE EXPERIENCES

Experiences of Receiving Welfare Benefits:

Insights from Estonia, Hungary, Norway, Spain and the UK

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and the WelfareExperiences team

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Main academic partners

King's College London (lead institution)
University of Kent, UK
Tallinn University
Praxis Think Tank, Estonia
Complutense University of Madrid
Centre for Social Sciences, Hungary
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Newcastle University
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The Poverty Alliance
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APLE Collective, UK
Estonian Chamber of Disabled People (EPIK)
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About the project

The Welfare Experiences project is an ambitious, innovative project comparing the experience of receiving benefits in five different countries: Estonia, Hungary, Norway, Spain and the UK.

The project will be one of the first international comparisons of the experiences of individuals receiving public benefits. We have come together in this project to pursue two shared goals.

1. Welfare policymaking needs to work in partnership with people receiving benefits, who are experts in their own right.
2. Welfare policymaking too often focuses only on financial incentives, and ignores the other things that matter – e.g. whether benefits provide dignity, security and feel fair; or whether people feel stigmatised, insecure, and unjustly treated. We want to make these 'experiences of receiving benefits' visible, and to start building an evidence base around them so that we better understand how welfare systems really work.

For more details of our goals, or to sign up for the mailing list, see https://welfare-experiences.org/ . The project runs from 2023-28 and is both mixed-methods and coproduced – find out more by looking at the Work Packages page. Our pan-European team includes eight different research organisations and seven organisations that work with people with lived experience of claiming – you can find out more about the Team here.

The WelfareExperiences project receives €3m of funding from the UK Research & Innovation Guarantee [EP/Y024621/1], having been selected by the European Research Council.

About the authors

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Executive Summary

This report is the first part of our effort to create an understanding of what 'experiences' of receiving benefits are, and which aspects of experiences matter for different people in and across countries. It discusses findings from 28 discussions groups that took place in 2024 as part of work package 1 of the *Welfare Experiences* project, with people receiving disability and/or unemployment or minimum income benefits in Estonia, Hungary, Norway, Spain and the United Kingdom. Workshops were designed and led by co-production research partner organisations in each of the nations, supported by the national academic teams as and when needed.

This report provides an overview of findings from work package 1 of the Welfare Experiences project, involving discussion groups with people receiving disability and unemployment or minimum income benefits, and will, together with an academic literature review, form the basis for the conceptual framework used in the quantitative and qualitative research on the project.

The key findings from these 28 discussion groups across five countries include:

Experiences of social security and benefits

- Institutions frequently fail to fulfil their fundamental duty of supporting and providing dignity to the lives of those most in need. When people shared their experiences of navigating systems and receiving benefits it became clear that experiences were largely negative with participants describing them as complex, inaccessible and inconsistent.
- Welfare systems were persistently characterised as burdensome, unpredictable and slow, demanding technical knowledge often beyond the reach of those facing crisis. Information provided was experienced as incomplete, hard to access and confusing, and the combination with this and a knowledge gap among many caseworkers often forces claimants to rely heavily on informal support networks and supporting third-sector organisations. Crucially it is not only the language and information that is inaccessible, but also, for some buildings.
- The administrative burdens go far beyond paperwork, manifesting as repeated humiliations where individuals must continuously justify their needs through invasive assessments and relentless verification. Furthermore, payment errors, shifting rules and limited support furthered financial struggles and insecurity.
- Long waiting times, for information, assessments and decisions, creates an environment of insecurity, unpredictability and precariousness that is associated with fear and worry.

- Geographic and institutional inconsistencies exacerbate these problems, producing a “welfare lottery” where outcomes depend on the luck of the caseworker or regional office handling a claim.
- Assessments related to rehabilitations and disability were experienced as particularly invasive, and caseworkers were often found to be lacking in knowledge and inconsistent, i.e. through different advice depending on which caseworker someone is seeing. This further adds to experiences of powerlessness, increases administrative burdens and unpredictability. Some positive developments were highlighted around assessments in Spain, where the introduction of in-home dependency was experienced as a more respectful and humane approach to assessment, and one that others could learn from. The increase of an empathetic approach was also noted in Scotland, where a shift in attitudes was experienced by those receiving benefits and in Estonia were participants also noted how respectful and empathetic caseworkers affected their experiences positively.
- While digitalisation was experienced positively by people who have digital skills and access to appropriate devices and the internet, some participants found that it introduced new forms of exclusion for those lacking technological access or literacy, adding digital barriers alongside bureaucratic ones.

Emotional impacts

- The emotional impact of these systemic failures is among the report’s most important findings. Participants described interactions with welfare systems that systematically erode dignity, security and justice. An example of this was disability assessments that demand physical exposure and caseworkers that treat claimants as suspects rather than individuals in need.
- Emotional impacts identified in the discussion groups include shame, anxiety, and powerlessness, with many depicting welfare experiences as sources of trauma rather than support. Shame, degradation, dehumanisation and loneliness were common emotions among those receiving benefits, driven by the experiences of surveillance, having to prove oneself and navigating a complex, longwinded labyrinth of processes. These experiences also lead to feelings of powerlessness, frustrations, a lack of control, and not mattering.
- Insecurity, surveillance and unpredictability also create an environment where those claiming benefits experience enduring worry, fear and anxiety.
- Particularly worrying are accounts of how navigating benefits worsens existing physical and/or mental health conditions creating a cruel paradox where systems designed to provide security instead generate further vulnerability and hardship.

- It is important to note that many participants expressed feelings of gratitude for the support they have received, however, this was rarely the only, nor the predominant experience or feeling after navigating an application process to receive benefits.
- When discussing what an ideal system would look like, there were remarkable similarities between the discussion groups in the different countries. These included wanting adequate levels of benefits, ease of use of applications, better caseworker support, shorter decision-making times, more accessible information, dignity through trust, empathy and respect not surveillance, safe, accessible, inclusive and welcoming spaces and processes.

Contents

Background

Welfare Experiences is a comparative, five-year project exploring experiences of social security of working-age people who are out-of-work across Estonia, Hungary, Norway, Spain, and the UK[1].

This report has been created by the co-production team, in collaboration with co-production partners and the wider international project team. It forms part of the findings and outcomes of the first work package. The other main output is a new theoretical model outlining a novel approach to analysing and understanding the experiences of those receiving benefits. The latter combines the results of an academic literature review and the findings set out in this report.

Placing lived experience and co-creation of knowledge at the heart of the project is a core principle of the research. The discussion groups were led by co-production research partner organisations in each of the nations between June and November 2024. In total, 28 workshops were conducted across the countries.

This report aims to create an understanding of what ‘experiences’ are and which aspects of experiences matter when it comes to the process of applying for and receiving benefits in and across countries. This report also explores the emotions that people receiving benefits associated with interactions with social security systems and specific benefits.
In this report, we delve into common experiences of social security systems and benefits identified in the discussion groups, including the complexity and opacity of systems, knowledge gaps, administrative burdens, digitalisation, surveillance, the emotional toll of waiting, onerous disability assessments, accessibility issues, and the inadequacy of benefits, often compounded by a climate of suspicion. After discussing these experiences, the key focus of this report is then turned to: how these experiences and interactions with the social security systems make people feel.

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[1] The project is being conducted in Scotland and England in the UK. Whilst both countries have the same out-of-work benefit, Universal Credit, Scotland has a devolved government and powers over a range of reserved matters. Since 2016, reserved matters have expanded to include some elements of social security.

Methodology

The research proposal for Welfare Experiences proposed a consultation approach with people receiving benefits, working with country co-production partners, third sector organisations in each of the countries who work alongside people with lived experience of social security. The aim of the first full project meeting was to co-design the approach to consultation. At this project meeting, co-production workshops/discussion groups were developed to identify a set of dimensions of welfare experiences, and of what experiences matter, by working with people receiving benefits.

Co-production started with co-production partners and academics working collaboratively on the funding proposal for the project. However, the work in practice started at our first cross-country project meeting in Madrid in February 2024, where academics and co-production partners began to explore approaches and methods that would capture experiences of applying for and receiving benefits. In the meeting, we explored creative and alternative methods to involve people with lived experience in research. We also discussed who should be involved in the research to cover a diversity of views, leading to a discussion on the barriers that could present when speaking to marginalised groups in specific countries.

A central tenet to co-production in the project is adaptability and flexibility, in practice meaning that the international co-production leads in the project would provide documents and guidance throughout, but that the national co-production organisations could adapt these to the groups and participants as they deemed necessary to meet the project aims. The research project team also developed guidance for the co-production organisations to support the organisation of the workshops which included ideas around participatory approaches/methods that could be adopted in the workshops. This included developing a discussion guide for the discussion groups which, after receiving feedback from the partner organisations, was finalised and translated for each country.

After approval from the ethics committee at King's College, the workshops were conducted by experienced researchers/practitioners from the co-production partner organisations: APLE Collective (England), Inclusion Scotland (Scotland), the Welfare Alliance - Velferdsalliansen (European Anti-Poverty Network Norway, National Federation of Associations of Disabled People - MEOSZ (Hungary), Estonian Chamber of People with Disabilities (Estonia) and Caritas (Spain).

As part of our co-production, and to prepare for discussion groups, the co-production lead, Trude Sundberg, qualitative research lead Erika Gubrium, and partner organisation, Poverty Alliance, delivered three sessions on safeguarding, self-care and trauma-informed training and on running focus group discussions.

Collecting the data

Discussion groups were conducted in the five countries between June and November 2024. The discussion groups were mainly held in-person and lasted between two and three hours. The discussion groups were designed to explore and identify experiences and emotions, and a set of creative methods tools were developed to help build rapport with participants in the discussion groups and help the researchers explore these often-difficult topics with participants.

The general structure of the discussion groups, although they varied by country, began by asking participants if they could share one or two words that came to mind when they heard the words 'social security' or 'welfare systems'. This was followed by asking whether participants had a key story that they wanted to share that reflected their experiences of social security. In the UK-based workshops, arts-based, creative methods were also utilised in the workshops as a tool for participants to share their individual experiences. To explore in-depth how people feel about their experiences, participants were also asked open, probing questions including questions about their journey claiming benefits, and questions such as:

- What feelings come up when you think of the process of claiming benefits?
- What is normally not talked about in terms of your experiences and feelings?
- What is hidden in terms of people's experiences of receiving the benefit?

Who did we talk to?

Table 1 below provides a summary of the number of participants who took part in the workshops in each of the countries. We were particularly keen to hear from groups whose voices are less likely to be heard, more likely to be marginalised, and sometimes referred to as those groups furthest removed from realising their rights. In discussions during the full project meeting in February 2024, we discussed the importance of ensuring diversity during recruitment for the discussion groups. Recruitment included a focus on the following groups in particular: migrant groups, LGBTQIA+ people, and refugees as well as rural and urban experiences. Socio-demographic data was collected for the workshop participants (see **figure 1** below).

Table 1: Workshop participants

Country	Number of discussion groups	Number of participants
Estonia	4	26
Hungary	6	24
Norway	3	26
Spain	10	51
Scotland	2	15
England	3	13

Figure 1[2][3]

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[2] In the socio-demographic questionnaire, participants were asked if they had any longstanding health problems or disabilities that limited day-to-day activities.

[3] Some socio-demographic data was not collected in Spain (disability/health condition, sexual orientation) and in Hungary (sexual orientation and whether born in country of residence). There is also some missing data on whether participants were born in country of residence in Norway.

Analysis

Discussion groups were recorded and the majority transcribed. Each of the national co-production teams had debrief and reflection sessions after each of the discussion groups. This fed into the analysis and writing of country reports for each of the countries in the project. To collate and manage the large quantity of data and to aid a comparative approach to analysis across countries, a simple framework was developed to identify data relevant to help create an overall conceptual framework for the project.

Limitations

This is the first of three stages of data collection on the overall project. Given its explorative qualitative focus, there are a set of limitations to the findings here, most crucially along two dimensions; missing groups of the populations in each of the countries studied as well as missing representations from geographical areas amongst participants in the discussion groups. There are some populations that we know we need to ensure we include in our next steps given other research has shown they experience negative attitudes and stereotyping generally in the societies studied, these include refugees, LGBTQIA+ individuals and marginalised groups. As we are just in the infancy of the project it is to be expected that we later identify parts of welfare experiences that were not present in these discussions, this is common when a new area of knowledge is mapped out.

Overview of country welfare systems and benefits

One of the project aims is to understand to what extent experiences vary depending on the welfare system in place in each country. Therefore, it is crucial that we set out an overview of the different systems so that we can discuss the relation between experiences and system characteristics in the discussion of findings. Here, we provide an overview of the welfare/social security systems and benefits across the five countries.

Table 2: Country sickness/disability benefits

Country	Sickness benefit/Disability benefit	Overview
Estonia	Work Ability Allowance (Disabled Adult Allowance)	Managed by the Estonian Unemployment Insurance Fund, requires a specific work ability assessment, making claiming complex.
Hungary	Disability Benefit Rehabilitation Benefit	The disability pension system was overhauled in 2012 to re-assess the health conditions and redirect recipient to other social assistance benefits and public work programmes with much stricter conditions. The new system distinguishes between Permanent Disability Benefit and Rehabilitation Benefit, time-limited (max 3 years) for those expected to regain work capacity.
Norway	Sick Leave Benefit Work Assessment Allowance	**Sick Leave Benefit:** Provides full wage replacement up to a cap for employed sick workers; widely accepted and carries less stigma. **Work Assessment Allowance:** National benefit for those temporarily unable to work; increasingly conditional and bureaucratically demanding.
Spain	Dependency Assistance	Based on an in-home dependency assessment, offers a combination of cash and direct care services to support people of all ages with different levels of dependency
UK	Universal Credit Personal Independence	**Universal Credit:** Means-tested benefit for low-income and unemployed individuals; combines several previous schemes into a single monthly

	Payment and Adult Disability Payment	payment. Online administration and strict job search requirements can create barriers and hardship. **Personal Independence Payment**: Provides cash support for disability-related costs but does not cover care services. Assessment is medically based and often seen as stressful and difficult. **Adult Disability Payment**: A Scottish Government benefit designed to support adults with disabilities or long-term health conditions. Administered by Social Security Scotland, ADP replaces the UK-wide Personal Independence Payment (PIP) for residents in Scotland.

Table 3: Country unemployment benefit/minimum income

Country	Unemployment benefit/ Minimum income	Overview
Estonia	Unemployment insurance benefit Subsistence Benefit	**Unemployment insurance benefit:** Contributory support for actively job-seeking unemployed people, with personal assistance available at local offices. **Subsistence benefit:** Means-tested benefit handled by local municipalities and the Social Insurance Fund – application involves calculation of subsistence level and is time-consuming.
Hungary	Employment Replacement Subsidy	Minimal income support for long-term unemployed not eligible for unemployment insurance. Requires active job-seeking and participation in public work programmes.
Norway	Social Assistance	A locally administered, means-tested benefit of last resort, often subject to discretion and associated with stigma.
Spain	Minimum Living Income Renta de Garantía de Ingresos (RGI)	**Minimum Living Income (IMV):** National benefit providing basic income support to low-income households not eligible for contributory unemployment benefits. Monthly payments vary

	Rentas autonómicas de inserción	according to family size and income. Applications are online-only with limited guidance. **Renta de Garantía de Ingresos (RGI):** Introduced in 1989, the Basque Regional Income Guarantee (RGI) is a means-tested, last-resort benefit that complements Spain's Ingreso Mínimo Vital (IMV) by topping up any shortfall to ensure adequate income support.
UK	Universal Credit	Means-tested benefit for low-income and unemployed individuals; combines several previous schemes into a single monthly payment. Online administration and strict job search requirements can create barriers and hardship.

Cross-Country Commonalities and Differences in Benefit Systems

There are key commonalities and differences between the benefits and systems in each country. While each country's welfare system is shaped by its unique institutional, political and administrative frameworks, several key similarities and differences emerge across the five countries studied. These differences relate to eligibility for benefits while in employment, the professional background of those conducting disability assessments, the structure and decentralisation of welfare provision and the degree of digitalisation in application processes.

- **Employment and Eligibility for Disability and Dependency Benefits:** In many of the countries, it is possible to receive disability and/or dependency benefits while engaging in some form of employment. For example, in **Hungary**, **Estonia**, **Spain**, and the **UK**, benefits are not necessarily conditional on complete withdrawal from the labour market. However, the rules and thresholds vary significantly. In the **UK**, under **Universal Credit**, claimants assessed as having *'limited capability for work and work-related activity'* are not permitted to work. By contrast, those assessed as having *'limited capability for work'* can undertake **"permitted work"**—a tightly regulated form of employment subject to earnings limits and other restrictions.
- **Decentralisation and Regional Variation: Spain** stands out for its highly **decentralised welfare system**, in which both the **generosity** and **administration** of benefits can differ considerably between autonomous regions. This means that access to support – and the form that support takes – may vary significantly depending on the claimant's place of residence.

- **Levels of Digitalisation in Application Processes:** The reliance on digital platforms for accessing welfare benefits varies across countries. In the **UK** and **Spain**, systems are **primarily digital**, with most applications and communications taking place online. While the UK does offer some telephone-based alternatives, these are limited and typically reserved for specific cases. In contrast, **Norway, Hungary, and Estonia** maintain more **flexible systems** that allow claimants to apply **either online or using paper forms**. This flexibility can help accommodate those with limited digital access or literacy, but it may also lead to uneven experiences depending on local implementation and support.
- **Disability Assessments:** The assessment for disability-related, illness and dependency benefits also varies by country and reveals important differences. In **Hungary**, evaluations combine medical examinations with reviews of applicants' work history and social circumstances. Applicants can choose between in-person or paper-based assessments, though participants report having limited options and often experience the process as intrusive and overly medicalized. In **Estonia**, assessments are conducted by public sector doctors. Applicants must submit a certificate from their doctor along with supporting documents – such as diagnostic reports and employment histories – to the Social Insurance Board. These assessments are reviewed at regular intervals, and individuals are expected to provide updated medical evidence each time. In **Spain**, face-to-face home visits are conducted by social workers employed in the public sector, particularly for assessing dependency benefits. These professionals use structured interviews that include questions about the person's ability to perform daily activities such as eating, dressing, or bathing. They also apply standardised assessment tools – Baremo de Valoración de la Situación de Dependencia – to evaluate the degree of support needed. The **UK** outsources assessments to private firms contracted by the Department for Work and Pensions. The Work Capability Assessment is carried out by healthcare professionals-via phone, video, or in person-who review a completed questionnaire from the applicant, ask questions about daily activities, and may perform a physical examination. These professionals write a report, on the basis of which the Department for Work and Pensions make the final decision and determines when reassessment will be required. In **Norway**, disability pension assessments are performed by doctors and often involve a lengthy process: typically, one year of full-pay sick leave, followed by up to three years on a reduced work assessment allowance (which can be extended in some cases). To be approved, a claimant must demonstrate at least a 20% reduction in work ability. However, claims – particularly those related to ME (myalgic encephalomyelitis) or mental health conditions – are frequently delayed or denied, forcing some applicants to rely on general social assistance while they wait.

Navigating social security systems: key experiences

Our discussion begins with participants lived experiences of navigating the various aspects and bureaucratic processes of welfare systems, from initial applications and assessments to ongoing compliance requirements. These interactions are often marked by complexity, uncertainty, and, at times, frustration or distress. We explore how participants make sense of these systems, how they negotiate eligibility and conditionality, and how they experience encounters with welfare officials or digital interfaces. We then highlight how these engagements extend beyond administrative hurdles, shaping the fabric of daily life – impacting not only material circumstances but also emotional well-being, mental health, and a sense of personal dignity. The cumulative effect of interacting with these systems influences how individuals feel about themselves and their place in society.

Participants' experiences of out-of-work employment, minimum income schemes, disability/sickness benefits and wider social security systems were largely negative overall. Across the countries, social security systems were variously described as 'broken', 'invasive', 'bureaucratic', 'inaccessible' and 'complex'. Yet, we also highlight moments of positive engagement, which, while less frequent, reveal important opportunities for cross-country policy learning. The following examines common features of the social security systems across the countries and how they were perceived.

Across the national workshops, participants described welfare systems as opaque, inconsistent, and difficult to navigate – demanding expert knowledge from those most in need of support. Complex bureaucratic processes, inaccessible digital platforms, and fragmented information channels often left claimants reliant on non-governmental organisations, peers, or informal networks to understand their rights. These systemic shortcomings were not seen as minor inefficiencies but as active sources of stress, delay, and exclusion.

Many participants highlighted how unpredictability – stemming from payment errors, shifting rules, and limited support – blocked routes out of poverty. Access was further impeded by language barriers, physical inaccessibility, and the erosion of face-to-face contact. Digitalisation provoked mixed reactions: while some welcomed efficiency gains, others experienced exclusion due to a lack of digital skills or access. Across contexts, decisions were often perceived as impersonal and disconnected from the realities of claimants' mental health struggles or everyday constraints.

Some positive developments were highlighted. In Spain, the introduction of in-home dependency assessments was praised for their respectful, humane approach, demonstrating that dignified support is possible within these systems. Similarly, in Spain and Estonia, participants noted the importance of respect and empathy, with staff acting as “enablers rather than gatekeepers”. In Scotland, participants shared positive experiences of the devolved agency responsible for delivering social security, Social Security Scotland. There was a distinct feeling that there was a positive shift in attitudes around disability and social security in Scotland compared to Personal Independence Payment delivered by the Department for Work and Pensions (DWP).

Complex systems

A common thread across the country workshops was the complexity of social security systems and poor information sharing by state agencies responsible for the delivery of benefits. Inaccessible digital systems and a lack of transparent information online were frequently mentioned. Navigating complex systems was particularly an issue for refugees and migrants who took part in workshops in Norway and Spain.

During the discussion groups in Hungary, participants reported that unclear or incomplete information frequently resulted in delays in submitting their benefit applications. In Spain, the process for applying for benefits was described as slow and emotionally draining. In the UK, participants reported that “knowing the rules” is hard to keep up with as they constantly change, and that the Department for Work and Pensions staff were often untrained. Across the countries, information about entitlement and support to navigate the systems was reported to come from friends, family, people in similar situations and non-governmental organisations. The following quote from a participant from Hungary suggests that the system has deliberately been set up to make it difficult to access benefits: *"I think the Hungarian state is out to make sure that people don't know what they could be entitled to and don't ask for it”* (Hungary).

Across all contexts, participants highlighted the need for advocates or ‘external specialists’, emphasising that navigating the system often requires expert knowledge: *“you have to be an expert to get support”* (Norway). Similarly in Estonia, participants needed to conduct their own research to discover their rights and other potential benefits. The officials appear to expect applicants to understand the complex system rules without providing any guidance. They felt that "*anyway they don't give you advice and they don't give you help*" (Estonia).
In the UK, the transition to Universal Credit was particularly challenging for some. One participant, with prior experience advising others on welfare entitlements, reflected:

> *“I used to advise people on welfare benefits. I used to so I really know the system really well and normally managed to navigate it really well and have been fine. But Universal*

> *Credit has just been really confusing. Terrible experience. It's made me quite ill to be honest, on quite a few occasions." (England)*

In Hungary, a participant commented on a complicated, unsupported system that did not respect the individual: **"***they don't give you the information that you really need – it is difficult to understand the legal background and process, not enough clarity in relation to the medical complex assessment (example cited with a person coming up to retirement) …"* (Hungary). Some migrants in Norway struggled with the complicated language Norwegian Labour and Welfare Administration (NAV) uses. Some also expressed how assumptions are made that immigrants know the things most Norwegians know – like what welfare programs are available or even how to dress for winter. This was not always the case. Immigrants to Norway said that they avoided using an interpreter because they believed the interpreter would spread sensitive information to their wider community.

Knowledge gaps and changing case workers

People receiving benefits across the countries shared struggles in relation to understanding benefits and social security systems due to the complex systems and inaccessible language of welfare systems. Knowledge gaps were also identified to sit with caseworkers and those providing benefits. This was highlighted as a key issue in the five countries, with discussion groups in Norway, Estonia and the UK particularly emphasising inconsistency and disparity in advisors' knowledge of systems.

Frontline staff – whether assessors or work coaches – had a strong impact on claimants' experiences, but interactions often felt like a "luck of the draw". Participants frequently expressed that everything could depend upon if you were lucky and had a good case worker, good doctor or supportive employer (in the case of sick leave recipients). Knowledge gaps were also partly caused by frequent changes in caseworkers. For instance, in Estonia, one participant directly stated that *"My experience really depends very much on which official you happen to get"*, affecting *"Whether they manage to make the process pleasant or unpleasant for you in the end"* (Estonia). Due to the complexity of the system, another participant found that *"each time is different*" when navigating it.

Luck was also echoed in workshops in the UK. For example, in one of the Scottish workshops, a participant recalled a positive experience of a disability work coach: *"Who knew a lot about blindness and vision impairment […] he just created a really good atmosphere for me and I think the protection and the wisdom of him stopped a lot of the stupid things happening"* (Scotland). These feelings were also expressed in Spain: *"They don't properly inform you about everything they do. Some do, some don't. It depends on the personal qualities of the person assisting you"* (Spain).

Feeling of randomness increases uncertainty among recipients. You could be lucky or unlucky, and there is very little perceived predictability. Furthermore, mentioned across countries and benefit types, frequent changes in caseworkers put pressure on recipients as they have to lay their soul bare again and again. This constant retelling is not only exhausting but also leaves them feeling exposed and vulnerable.

Across the countries, participants reported that caseworkers lacked understanding of disability. In the UK, participants said that Department for Work and Pensions staff showcased a fundamental lack of understanding around disability and long-term illness. In Estonia, a participant stated: *"They actually cannot guide me in this matter".* In Norway, participants commented on the lack of knowledge of caseworkers on issues or illnesses that were different than the 'bogstandard' ones. Positive experiences with knowledgeable and compassionate front-line staff significantly influenced how claimants felt. However, the ability of case workers to offer meaningful support was often limited by being overstretched and under-resourced. As one participant in Norway put it, *"they don't have time - they have so much to do"* (Norway).

Lack of awareness and knowledge gaps were also a key issue when it came to the knowledge of those receiving benefits. In Hungary, for example, participants reported that people are not aware of their rights or benefits that they are entitled to, which was described as *"a form of discrimination"*. Gaps in outreach and raising awareness of benefit entitlement was also a key theme. Participants noted that information about benefits was often accessed through informal networks, friends, family, self-organised groups (e.g. Facebook), colleagues, or NGOs. One example involved a young wheelchair-using participant who only discovered the option to recalculate their disability benefit through a conversation with their workplace receptionist. In Estonia, participants needed to conduct their own research to discover their rights and other potential benefits. The officials appear to expect applicants to understand the complex system rules without providing any consistent guidance.

A similar pattern emerged in the Spanish discussion groups. Many participants said they first heard about the minimum income benefit through friends or social workers, rather than official channels. They also found the eligibility criteria and rules around working while receiving the benefit confusing and opaque, which led to anxiety about potential denials or sanctions. In the Spanish discussion groups, many participants said that they had found out about benefits through friends and social workers.

Inaccessible language, that is too complicated to understand, was also a common theme across countries, with many pointing to a need for advocates or support to be able to navigate the system. As one participant in Spain shared: "*Just yesterday, a postman came and gave me a letter with four pages... I read it ten times and still don't understand it*" (Spain). In Estonia, a participant shared their deep frustration with the language used on the website: *"It is very difficult for me to understand, there are very few things there in human language for me"* (Estonia). One Estonian participant described reading the website and feeling their "*wire [brain] snapped*" and consequently needing someone who used to work there to explain it: *"I couldn't understand anything".*

Similar feelings of impotence were voiced in Hungary: "*I understand it's written in Hungarian, but it's a bit fancy*" (Hungary). Our work with organisations that provide this type of support meant that a sense of gratitude to those organisations came up quite frequently as a counterweight and in sharp contrast to how the welfare system supports them.

Administrative burden and inconsistent support

Participants across the countries experience inconsistent support characterised by high administrative burden which created and led to negative effects on their wellbeing. A high administrative burden was a common description of welfare systems as participants experience having to report in detail about their lives, experiences leading them to apply for benefits, and about their financial situation.

Participants across the UK, Spain, Estonia, Hungary, and Norway reported facing significant administrative demands during their interactions with welfare systems. These included multiple interviews, detailed forms, and ongoing requirements to submit documentation to prove eligibility.

In the UK, claimants applying for Universal Credit described a process involving an initial interview, lengthy questionnaires, and further assessments, often feeling as though the system was designed to make you feel like you are under suspicion. UK participants highlighted a lack of individualised support and rigid processes that did not take personal circumstances into account. For example, one claimant was required to attend a training course despite facing discrimination during the sessions. Their subsequent exclusion from job referrals created further complications with the job centre.

Applicants for disability benefits in the UK encountered additional scrutiny. One participant described needing to provide medical documentation and even to bring a psychiatrist to an appointment to verify their condition, only to be asked for further proof of the doctor's credentials.

In Norway, all groups had to submit paperwork regularly, but for those on social assistance, this could be invasive, with an example being the requirement to submit bank statements. Recipients were unable to receive gifts and even had issues with people paying things like rent or repaying loans which were misinterpreted as income and resulted in a deduction. Those with obvious long-term disabilities had to fill out forms proving they were still disabled year after year, increasing the burden on those who are already struggling with long term illness and disabilities.

By contrast, in Spain, where there is less conditionality once accepted for the Minimum Income (IMV), participants report very little follow-up after receiving the benefit. Some expressed frustration at the lack of training or job opportunities offered, which left them feeling stuck and without clear paths forward.

A crucial experience with the system in Norway, which might be worth exploring more in other countries was the lack of synergy between benefits – some benefits paired poorly with each other. Rental assistance (bostøtte) increases could result in a reduction in social assistance payments, and the gap made the increase negligible. Some participants expressed that case managers don’t know what you are eligible for, nor do some doctors in the case of sick leave/WAA. Switching between benefit types (which was common) meant learning entirely new logics and vocabularies, and processes.

Digital systems

In the discussion groups, there were mixed views of digital systems. Participants critiqued the loss of face-to-face communication with the move toward digitalisation; some missed the trust building that was possible through face-to-face communication. This also could cause less misunderstandings, some felt. Decisions were often felt to be made by ‘higher ups’ who don’t ever meet the person. Lack of direct phone numbers for contact was frustrating and time consuming. However, some (especially younger participants) felt digitalisation was positive because they could obtain help from ChatGPT in formulating responses or understanding complicated jargon.

In Hungary, most participants agreed that digitalisation is a very good solution for people, in particular for disabled people, as all social benefit claims can be submitted electronically. Thereby easing the burden of applying for this group. Many of the participants took advantage of this opportunity. The Hungarian discussion groups did have a high number of people with physical disabilities, and this positive reaction was quite common in the Hungarian groups.

In Norway and UK, some participants appreciated digital options while others struggled with them, with age seemingly being an indicator for who feels digitally excluded and who is positive to these types of solutions. For example, in Spain, participants perceived digital obstacles to exist for older people and people unfamiliar with digital systems. For those who encountered these barriers, the application experience took an emotional toll:

> *“I actually cried while going through the application process. And on top of that, the whole thing is only online, right? Just online. Eventually, a worker from [the support organisation] who helps with paperwork stepped in to help me. She does these applications all the time since that’s her job, but she still spent half a day with me. I mean, we spent over four hours just submitting the application. Yeah, even for people who do this kind of work regularly, it’s tough... For me, it was really difficult.” (Spain)*

Furthermore, there were worries of lack of confidentiality, and breaches of confidentiality in Norway where caseworkers have access to a wide variety of personal history. The Estonian participants recognised the advancement in digitalisation; they stated that most of the benefits are mainly used online. Some of the Estonian participants shared the same concerns as those from Spain, Norway and the UK regarding digital exclusion, some participants felt that the online forms were too long and complicated to fill and that there is a need to enhance the usability and clarity of the benefit related websites.

The following quote from a participant from Estonia states that using digital systems depends on digital literacy: *"If you know and can use them, then it is good, but if you don't know and can't, then it is complicated"* (Estonia).

In Estonia, multiple participants commented how digital platforms such as eesti.ee have expanded their function to include benefit application submissions. The development received positive feedback because it shows promise to minimize the requirement of government office visits especially for people residing in distant rural locations. People valued the ability to begin and finish applications through online services at their own convenience.

Long waiting times and waithood

Temporality and waiting are a central part of applying for and receiving benefits as participants report long and uncertain waiting times where decisions are felt to be random (particularly emphasised in Norway, Spain and UK). Participants reported that everything from applying for benefits to communicating with case workers and submitting documents took a lot of time and effort. Issues related to temporality differ depending on type of benefit recipients are applying for, and across countries, however waithood and uncertainty is part of application processes across countries. When it comes to temporality there is also a crucial finding in Norway, with some participants remembering a better system in the past where caseworkers were specialists in their area, contributing to a nostalgia for what was. The uncertain waiting time creates a context of before and after and is a criterion of difference between receiving and claiming benefits, and potentially of judging someone's deservingness.

After enduring long delays, participants expressed feeling caught in a cycle of uncertainty, where limited guidance on combining benefits with work and fears of sanctions or forced reapplications – especially concerning the Ingreso Mínimo Vital (IMV) in Spain – caused apprehension about beginning the process anew. This is crucial to note due to the particularities of this benefit as discussed above. Recipients fear losing their benefits or ending up with less income if they take up a job.

A participant in the UK vividly illustrated how the prolonged uncertainty associated with waiting for a response can take a serious toll on both mental and physical health. The lack of clear communication and constant ambiguity around the status of a claim contributed to a heightened sense of anxiety and distress:

> *"Oh, physically and mentally. Like mentally you feel like anxious, depressed, and when you're not sure what's going on with your benefits it can even make you feel well like you are having a breakdown because you're like, well, I don't know if it's getting reviewed and I don't know if it's gone through, or I don't know what's the progress on it." (England)*

Disability/sickness benefit assessments

Participants experienced disability and sickness benefit assessments critically across all countries, although there were some positive perceptions in Spain. In the Norway, Estonia, UK and Hungary groups, participants discussed the burden put on people who are ill to prove they have a health condition.

Spotlight on the UK
People applying for UC with a disability or health condition must complete a work capability assessment either online or in person with a healthcare professional from a private organisation. The main issues and experiences which came up during workshops in Scotland were that the approval process required multiple forms of verification and information, which caused stress and unease for claimants. Second, the interactions with staff during the assessment process and afterwards were tinged with hostility. Many felt that their benefits could be revoked during these sessions and were made to feel as if they were trying to overclaim.

Another aspect of assessment was that the assessment for the disability elements was often a way to 'catch out' those who were not considered disabled enough by DWP staff, and that this showcased a fundamental lack of understanding around disability and long-term illness. A participant described the Universal Credit assessment process in the UK as 'barbaric' and did not consider their needs as a disabled person. When asked about the process, they said of their experience:

"I told them on the form that I couldn't attend an in-person assessment and they would not accept that and in the end, I had to travel into Glasgow to go to an in-person assessment. By the end of it I was sliding off the chair." (Scotland)

The assessment was not perceived as a tool to ensure participants are fairly assessed and receive the support they are entitled to, but rather as a distressing process that actively contributed to the deterioration of their physical and mental health.

Spotlight on Estonia

Participants in Estonia described the difficulty of demonstrating their conditions due to the extensive and detailed documentation required. Participants noted that even medical professionals may not have sufficient knowledge about the work ability assessment process and that information about it is not consistently shared. Incomplete or imprecise explanations could lead to assessments that failed to fully capture the extents of people's impairments or long-term health conditions. A common challenge was securing specialist medical appointments within tight deadlines, sometimes forcing people to turn to costly private healthcare. Repeated assessments for people whose impairments or long-term health conditions are not expected to change were seen as frustrating and unnecessary, with claimants often needing to prove the same issues multiple times. Some assessors lacked expertise in specific conditions, which undermined the credibility of evaluations. Participants criticised the system for reducing benefits based on minor health improvements while overlooking ongoing severe impairments.

Successful claims relied heavily on the accuracy of electronic health records. The process itself was described as stressful and invasive, particularly by those with mental health conditions. Many feared losing their disability status and financial support, especially given the inconsistent outcomes produced by different assessors interpreting the same evidence in varying ways.

"Yes, especially as stress is a significant factor that often - in our case, for example - exacerbates mental health problems. If you have a mental health disorder and are on benefits, applying for benefits can often make things worse."

Spotlight on Spain

In Spain, participants often experienced the assigned grades of dependency – Moderate, Severe, and High/Extreme – as inconsistent or misaligned with their actual needs. However, experiences of the in-person dependency benefit assessments were generally positive. These assessments were typically carried out by trained healthcare support workers who visited applicants in their homes or places of residence. In the focus groups, participants reported that they were treated with respect and empathy. They contrasted this encounter with other, more bureaucratic encounters within the broader benefit system, expressing appreciation for the more personalised and humane approach of the home-based assessment. This suggests that adopting such practices elsewhere could help reduce stress and improve claimant wellbeing.

Accessibility

Participants reported issues of accessibility when it came to accessing buildings, in particular, access that is crucial to be successful in applications for benefits. Reports included that buildings may have inclusive design features such as ramps, but not appropriate parking, don’t always have lifts and if they do, there may be an intercom system and may require another person to gain access. In the UK, one participant vividly recalled this distressing experience:

> *“So when I got to the job centre, they told me the person I needed to see was up the stairs and I asked where the lift was and there wasn't a lift. By the time I got to the stairs, the security guard to the top [had] to catch me and go and get a chair for me.” (Scotland)*

A similar experience was reported in Hungary, where buildings often lack ramps, accessible parking, or lifts: *“You know the lift is no good, they don't have a ramp, they get 3-4 people to pick you up. It's actually sometimes infuriating and anxiety-inducing to see if they can carry you”* (Hungary).

These issues were often worse in rural areas. Beyond physical barriers, participants also reported accessibility challenges related to communication and service systems. One LGBTQ+ participant with autism described difficulties booking appointments due to inaccessible online and phone systems, which forced them into uncomfortable in-person visits.

In Estonia, a significant distinction appeared when participants discussed the process of obtaining family doctor services. A participant experienced better success in locating a family doctor in her two-doctor town compared to potentially more crowded urban areas. Multiple participants expressed serious concerns about the insufficient specialist medical services which feature restricted availability and extended waiting periods for appointments. The location of certain specialists in bigger towns creates difficulties for all people but rural residents face unique challenges because they must overcome longer travel times, higher costs and more complicated logistics to reach their appointments.

Inadequacy of benefits

In Spain, Estonia and Hungary, there were discussions of the inadequacy of the amount received on benefits, an area that caused further stress and anxiety. Due to the differential levels of minimum income, IMV, in Spain this varies according to which state participants live in, with participants in the Basque Country receiving higher levels of benefits. Overall, participants in Spain felt that benefits *"are not focused on helping people out of vulnerability"*. As one participant remarked*: "The longer we stay in precarity, the more intense it becomes."*

In a similar vein , a participant in Hungary noted that minimal payments produce endless precarity: 'I know a lot of people anyway who have never been able to work, never will be able to work, and that's about why they're locked into the position of getting these minimal amounts of money and not really being able to get money any other way.' In the UK, a participant echoed the same experience: *"On benefits you are pinching every penny, scraping every penny, and sometimes, especially if you're only under one benefit, you don't actually have enough to live for the whole two weeks or month"* (England).

An effect of the perceived low level of benefits was the experience that benefits do not offer pathways out of poverty, and recipients fear losing them if they return to work, despite their desire to do so.

Similarly, in Norway, the social assistance system was perceived as lacking real support, as participants reported insufficient support with finding work or achieving long-term goals such as education and integration – unlike with work assessment allowance (WAA) in Norway. With 'dialogue meetings' (with recipient, doctor, employer and the state) for sick pay recipients, some felt they were beneficial, while others felt the meetings were intimidating and impersonal.

Surveillance & suspicion

Participants raised concerns about being treated with suspicion in the process of applying for and receiving benefits. There was also a strong sense of being under surveillance where those providing benefits ‘needed to see everything, including your bank details and your personal history. In Norway, there were concerns about confidential information being leaked, and a sense of powerlessness if that was to happen. Participants there also reported feeling “suspected or like a criminal”. In the UK, a participant shared the same feelings:

> *“People are worried when they have to go to the Jobcentre, because they feel like as soon as they walk through the door they're judged straight away. You get someone coming up to you saying, have you got an appointment? What time is it? As soon as you walk through the door you feel that atmosphere.” (England)*

The worries around surveillance were exacerbated by experiencing the system as one where errors occur, and where sanctions are common, which together leads to negative emotional impact and worsened mental health as described below. In the UK, a participant got a phone call from the Department for Work and Pensions about his savings, where they told him he had £15,000 in his account, which he did not. The fact that the Department for Work and Pensions had access to bank accounts and could make such egregious mistakes regarding the amounts of money that people had in them made participants afraid. As the same participant said: *“In the bank? I said, listen mate ‘I don’t have 15 hundred in the bank. The punchline is: they just have the authority to go and pry into my personal details, absolutely nae warning whatsoever.”*

In Estonia, participants felt they had to modify their behaviour and appearance during assessments: *“I made myself very humble.”* Participants felt their case workers acted more like the “police” rather than being helpful: *"What is important is that this social worker should not be a police … they should be supportive.”*

Another described feeling like they were "*under investigation by counter-intelligence.*” Some participants were subject to intense scrutiny of their bank records, comparing the process to a security investigation, a process that involves intense scrutiny of finances. They said: *"They check, they check…", and "this dance is around the bank account". Bank statements are submitted, and officials "start flipping through it line by line", asking, "but what are these things… but what are these?”"*

In contrast, most participants in Spain reported a lack of follow-up after receiving benefits. Those receiving the higher levels of regional minimum income in the Basque Country described experiencing greater control over their everyday lives, highlighting the difference an adequate level of minimum income can make to those receiving benefits.

Migrants in Spain often face significant barriers in accessing the benefits they are entitled to. Many lack awareness of the programmes available to them, often due to linguistic, cultural, or systemic challenges in navigating complex bureaucratic systems. A common sentiment among migrants is the absence of familial support networks, which exacerbates their reliance on external assistance. As one participant noted: *"Most of us here are foreigners and alone. If family is far away and can't help, we have to rely more on charities" (Spain).*

In addition to societal prejudice, procedural barriers further hinder access to benefits. They were often required to provide certified documents from their home countries, which don't exist or can be difficult to obtain and lead to delays in processing applications. A further barrier was the struggle to provide formal proof of residence as they mentioned difficulties in accessing formal housing arrangements in the context of a housing crisis. A participant in Spain shared that struggle:

> *"When it comes to housing, without that, you're stuck. I spent more than three years trying, but since I couldn't get a proper rental contract. I was missing a requirement and couldn't move forward. I lost four years ... How did I manage? Well, Caritas was helping me. I took courses with them too, and I was working off the books. But with two kids, it was really tough." (Spain)*

In Bilbao, where participants (mostly migrants) were receiving regional benefits, they faced difficulties meeting the required proof of residence (three years, compared to one year for the Minimum Living Income [IMV]). Obtaining a formal housing contract, which is a prerequisite for verifying residence, proved challenging for many. They also complained about more 'control' from the administration which included invasive visits to their home to prove that they were residing there. Participants also shared that they were often offered training and job opportunities that did not match their skills and employment histories.

Discrimination

Migrants and refugees who participated in the workshops in Spain shared experiences of racist and anti-immigrant attitudes. One participant stated:

> *"Let's be honest; most people think badly about those who claim the RGI [Guaranteed Minimum Income]. Most of them think that you're here just for that, that you only claim benefits. They don't know there are people who genuinely work. They don't know this. They think you're here just to take their help. They call it their help." (Spain)*

A participant recounted derogatory comments overheard on public transport: *"On the metro or the bus… they say, 'These people from outside only come here for the RGI [regional benefit]'"* (Spain). Another participant shared a similar experience during a bus ride where she heard a woman saying: *"Look, they come here just with kids and 'handouts'"* (Spain).

Migrants and refugees also feel scrutinised for their possessions or efforts to improve their livelihoods. Nadia explained:

> *"They look you up and down, and it's even worse if you have a car to get to work. They think that just because you're getting benefits, you can't own anything good. Imagine this: you're claiming benefits, then you find a job and buy a car to get to work. But they still look at you as if you're just living off the system" (Spain).*

How do social security systems make people feel?

This section examines the emotions of navigating welfare systems across the five countries, focusing on how different stages of the benefits process – application, assessment, and ongoing interactions or lack of them – shape the feelings and well-being of people receiving benefits. These emotions stem from a range of structural and procedural issues highlighted above. Many participants described the strain of inadequate support and a pervasive climate of suspicion, which compounded feelings of shame, worry, anxiety, powerlessness, vulnerability and gratitude.

Shame: degradation, dehumanisation and loneliness

Across all five countries, participants shared experiences of feeling degraded, dehumanised, and made to feel invisible within welfare systems – experiences that often gave rise to profound feelings of shame, social stigma, and isolation. These negative emotions stemmed from experiences of surveillance and intrusive documentation demands, widespread distrust, and being stereotyped as welfare cheats, as well as from the loss of identity tied to no longer being recognised as workers.

Participants shared features of surveillance in the system including invasive documentation demands leading to feelings of degradation and dehumanisation. Furthermore, participants shared that they were treated with suspicion of being 'welfare cheaters'. At the beginning of their claim for Universal Credit in the UK, one participant stated:

> *"You do feel ashamed and {like} nothing. I've just migrated to Universal Credit and had an {initial} interview, then had to fill in a form, then had another interview that lasted 1hr 10 mins. It just feels like to me, that they are trying to catch you out... and I just feel guilty, even though there is nothing to feel guilty about... and the stigma." (England)*

When reflecting on the comments raised within the three conversation workshops that took place in different locations in England, the reflections raised by different groups aligned in so far as participants felt dehumanised, the process was not person-centred and there was an acute lack of understanding of needs, which were not met or even considered. For example, a participant shared their experiences about 'being made' to do a course despite the abuse they received:

> *"During pre-transitioning, so at the time, for all intents and purposes, was a gay male, or at least a male in a gay relationship. I turned up to this place and within the first week, I was told by people I was on the course with that they did not want me there, they didn't want my kind, and they just didn't like me. I was even told by people running the course, that there was no point in me even trying to approach this as a job because of my*

> *situation – no one would hire me and I would receive abuse on a regular basis to the point of it not being worth it. I said I don't have a choice about being here because the job centre has made me do it. And when I finished the course, I was basically blacklisted almost immediately from the group that was to provide work. That then became a problem at the job centre." (England)*

In the UK, a participant described the disbelief and skepticism they encountered when seeking disability benefits. Assessors refused to accept that their psychiatric doctors were legitimate professionals:

> *"I actually got the psych team to ring them up and have conversations. I was like, here's the psych person, you can talk to them, and they were like, we don't believe they're doctors, and we need their actual qualifications before we can process it." (England)*

Despite their efforts, the scrutiny persisted. They continued:

> *"They thought I was scamming the system. I even took one to the appointment. Someone accompanied me, and they still didn't believe it—even though she had all her credentials. We knew this might happen, so we brought everything with us, but they still said, 'No, we think you re scamming us.' What more could I possibly do? How else could I prove it?" (England)*

In Hungary, several disabled participants shared feeling humiliated when accompanied by another person during reviews or assessments: *"Officers/assessors speak to the person who accompanies you more often than not. I think that's the worst"* (Hungary)*.* This intensified the sense that the welfare system is infantilising*: "I always get the feeling with benefits like this that it's as if they're doing us a favour, they're not really there for us, they're just doing us a favour"* (Hungary).

In Estonia the participants felt that they had to "act" or present themselves in a certain way to obtain benefits as discussed above. One participant described the experience as akin to being under surveillance by the 'Kapo' (Estonian Security Police) because her bank statements were inspected so thoroughly.

In Spain, guilt and shame appeared internalised and oppressing participants' desire for independence, as receiving help is seen as a source of personal discomfort and participants felt judged when being outside their homes. Several participants in Spain described feelings of being judged by society and being stereotyped as lazy. One participant shared an experience that illustrates this stigma:

> *“Last Christmas, I got on the bus with a friend of mine. She has three children, and I have two.”* [And a lady told her] *‘Look, they come here only with children and 'handouts’. Some people even look at you… Like the way you dress, they look at your phone. It seems like because you work, you can buy yourself a phone. But because you receive the benefit, you can’t buy anything good.” (Spain)*

These sentiments were closely tied to a loss of identity, particularly among those no longer in employment. Participants receiving the Minimum Living Income [IMV] in Spain often emphasised how important their past employment was to their sense of self. Many expressed a strong desire to return to work and felt that more support in doing so was needed. A participant shared: *"I already told the social workers that I didn’t want them to give me anything, that I wanted to earn it"* (Spain). Participants in Spain detailed experiences of both internal and external processes of stigmatisation. As one participant shared: *"I’m not lazy because of my situation, for example, I have to take care of a lot of things and not just my house and children"* (Spain).

Participants also described how societal stigma became internalised as self-blame by some participants: *“I do feel socially stigmatised, even by my own family. But I also feel stigmatized by myself. You end up judging yourself. I judge myself too. There have been times when I've thought, why can't I do this? Why is this my fault? Why can't I succeed?”* (Spain).

Another important aspect that emerged in the Norway workshop with people on sick leave benefits was loneliness and isolation. Some participants felt unable to socialise due to fear of being perceived as “well enough to work” or because of the stigma attached to receiving benefits. This fear also extended to everyday activities like grocery shopping, which some avoided to prevent appearing “too healthy.” This is closely linked to the internalised shame and external stigma of receiving benefits that was also discussed in other countries.

Worry, fear and anxiety

Fear and worry were commonly shared emotions by participants across the discussion groups in most of the countries. Fear and worry were often a consequence of uncertainty during benefit waiting periods as to whether an individual would receive a benefit and worry around whether or not they have submitted the correct information or made a mistake on the forms. This highlights how features of the different systems and benefit types impact participants’ emotions. Waiting periods were also a source of stress, uncertainty and feelings of exhaustion. Unpredictable payments, bureaucratic obstacles and a lengthy application process left people feeling emotionally drained. This exhaustion is exacerbated by the combination of difficult, complex and time heavy burdens of navigating benefits processes and the fear and uncertainty.

To a certain extent, participants felt grateful and relieved but remained critical, as the amount of the benefit does not guarantee dignity. However, due to financial uncertainty and “everyday being a challenge”, feelings of anxiety and depression became apparent. In the Spanish workshops, one participant stated: *"It generates anxiety for me. Because of course, you don't know if next month... I mean, you make your calculations of everything you have to pay, like rent, electricity, what's going to be left, what's not... so I can organise myself"* (Spain).

The impossible task of stretching inadequate benefits was highlighted as a constant source of anxiety in both Spain and the UK. Fear of penalties or financial sanctions also came up in the discussion groups. For example, in the Spanish discussion groups, many participants shared worry about penalties and repayment demands for overpayments due to administrative mistakes, or sudden cancellation of benefits. A participant in Spain noted how this intensifies feelings of insecurity: *“It is not a safe place (...) Today, I know I will get paid, but I don’t know about tomorrow”* (Spain). This was echoed by another participant in the UK: *“you sort of think, am I gonna get paid? And then you get paid, and that anxiety goes yeah, so I understand that totally. That's an underlying feeling that you don't actually think that you've got.”* Feelings of fear about potentially losing support were also evident in the workshops in Estonia, as one participant expressed: *"I have a big fear of taking a step when you know that the money can be taken away at any moment”* (Estonia).

In Spain, extended waiting periods for benefit approval were especially prolonged, making the experience emotionally exhausting and leaving recipients in a constant state of anxiety and uncertainty. One participant powerfully conveyed the emotional, material, and health-related toll that this prolonged waiting can take:

> *“It shouldn't take five or six months, leaving you in anguish, not knowing if you'll make it to the end of the month, relying on the food bank, where there’s hardly any fruit, vegetables or fresh food ... My two-year-old son had cavities in his teeth, and I’m sure it was because he was eating poor-quality food, you know? We did have food from the food bank, but we were eating pasta, rice, and canned tomatoes. That’s it, you know? We ate very little that was actually nutritious.” (Spain)*

In the UK, Estonia and Norway workshops, participants who were disabled or had a health condition were fearful that their benefits could be revoked if they were not ‘sick enough’ or ‘disabled enough’. As one participant in Norway ironically remarked, *“You almost need to send a death certificate to get disability insurance”* (Norway).

Feelings of fear and worry were often connected with feelings of powerlessness/helplessness. Whilst in receipt of social security, feedback from the three conversations in England continued to highlight feelings of fear and mistrust of work coaches (civil servants who deliver the benefits system) and the regime. Conditionality invoked anxiety and worry, with claimants “feeling under investigation” and commenting on the need to always “watch what they were saying”: *“There are so many things that I want to say {when I go into the job centre} but you just think, I can’t say that, they might make my experience horrible, or I might be sanctioned or lose money and it’s just that fear of not being sure what is going on”* (England).

Powerlessness: confusion, frustration & lack of understanding

Across countries, participants described a sense of powerlessness rooted in confusion, frustration, and a lack of control over their own situation and understanding of the benefit system. In the conversations held in Hungary, invoked feelings of confusion were linked to people not fully understanding who “gets what and why”. This was reflected throughout the various stages of the benefit system and felt by the different demographic groups participating (applying and reviewing). Negative feelings associated with the lack of a person-centred approach led to comments of claimants feeling humiliated, judged and labelled. As one participant in Hungary described: *"When I applied for disability benefits, I was looked down on like I was some kind of parasite"* (Hungary).

People with additional support needs talked about how they felt “ignored” and “dismissed” (sight impaired person) which led to feelings of embarrassment. Comments were raised in relation to feeling degraded. One participant shared “having to pull pants down” for an assessment. Echoing this, a participant who is a wheelchair user shared their experience: *“For me, everything, every interaction was terrible. I felt no autonomy. Having someone else control my existence and financial situation. I think it's humiliating”* (Hungary).

In Spain, participants felt like if they were reduced to a mere statistic, highlighting experiences of powerlessness and the lack of personal recognition within the system: “*I don’t know, it’s like they don’t focus on understanding people’s real lives — we’re just numbers. I feel like a number”* (Spain).

In the UK, one participant described how the dysfunction of the welfare system - and the overwhelming feelings of powerlessness and helplessness it produces - become somatised, taking a serious toll on both mental and physical well-being. In its most extreme consequences, they warned, this becomes life-threatening:

> *“I genuinely feel that there's been massive loss of life because this system doesn't work properly, it's not just it's it's not functioning properly .... I genuinely believe it's killing people off. I genuinely think it is. And it desperately needs fixed. Yeah, I think it has. I'm*

> *not saying it's deliberately set out to. That's not what I mean. But it's so dysfunctional that it actually kills people. I'm positive of it because it nearly killed me."*

Vulnerability

Feelings of vulnerability were closely related both to fear, shame and lack of control. However, there was a particular quality to what was spoken about when it comes to vulnerability, namely the laying yourself bare and having to repeatedly do so. "Re-telling stories" was exhausting and made people feel vulnerable across countries. Conversations in Spain highlighted that most participants applied {for benefits} after having experienced poverty and deprivation. While the benefits have improved their situations, they remain critical, as the amounts are insufficient to ensure dignity and get them out of poverty (it is important to note that this was only brought up when they were directly asked about it). Participants in Spain see the model and its management methods, as creating very negative experiences and feelings.

Gratitude

In Norway, and to some extent in Spain and Estonia, some participants stated that they felt "grateful", "privileged" and "lucky" to live in a country with a relatively good welfare system. These participants told how they felt thankful despite bad experiences in the system. In Spain, some participants felt grateful as IMV had been introduced recently and they acknowledged that things had improved.

In Estonia, one participant expressed a mix of gratitude and relief upon receiving aid: *"Of course there is help. Can pay again, yes, I am still grateful"* (Estonia). They also described feeling "*good again*" after receiving compensation for their expenses. Support was regarded as "*still extremely important*," playing a crucial role in helping people "*move forward."* Rather than just financial assistance, the support was experienced as a form of "*compensation*" that "*justifies your limitations*," helping to remove the "*feeling of shame"* and providing a vital sense of validation.

Some participants in Spain also expressed feelings of relief and gratitude upon receiving benefits. The following quotes reveal a complex blend of frustration over the insufficient financial support and appreciation, illustrating how even limited support can offer a crucial sense of social connection: *"It's not enough, but for me it's better than nothing." "You don't feel so alone... Exactly. You don't feel so alone. So... I don't know... That... I... Thank you very much"* (Spain).

In Norway, for participants receiving sickness/disability benefit (Work Assessment Allowance) feelings of gratitude, for some, stemmed from having a comparatively worse, less good experience of benefits systems in another country.

Ideal systems

The discussion groups concluded by asking participants about what their ideal journey through the social security system would look like: how would they feel and how they would be treated?

Most of the discussions focused on how problems with current systems and individual benefits could be improved. In the workshops in all countries, participants shared recommendations around improving interactions with civil servants and state agencies responsible for delivering benefits. In Norway, participants suggested a re-evaluation of office layouts to enhance claimant privacy. In the Spanish and UK workshops, participants discussed the role of civil servants responsible for administering benefits. In the UK, participants stated that Jobcentre staff should be offered training in person-centred support and take a differing approach prioritising respect, dignity and security over punitive measures.

Relatedly, in Norway, participants with immigrant backgrounds called for “cultural sensitivity” in service delivery. In both Spain and the UK, the need for social security systems and benefits to be more nuanced and holistic in support for disabled people was also discussed: disabled participants wanted their specific needs acknowledged rather than being subject to a standardised approach. Participants in Scotland recommended that medical assessments be undertaken by trained medical professionals, rather than retired army doctors or social workers with limited medical training. In Estonia, participants stated that government agencies must exchange information effectively to stop applicants from facing separate systems that force them to repeat information submission. In Norway, participants in the social assistance workshop strongly suggested a mentorship programme to provide guidance on navigating the system.

Conclusions

This report provided an in-depth analysis of welfare systems through the narratives of participants with lived experience from five European countries. It reveals how these institutions frequently fail to fulfil their fundamental duty of supporting and providing dignity to the lives of those most in need. The study exposed how bureaucratic complexity, systemic inconsistencies, and entrenched cultures of suspicion combine to create oppressive administrative labyrinths that claimants must navigate simply to access basic assistance. By sharing the voices and lived experiences of those interacting with welfare systems, this report highlights how institutional deficits perpetuate emotional hardship, economic instability and social exclusion, compromising health and well-being across affected populations.

At the heart of participants' accounts lies a pervasive sense of institutional dysfunction. In Spain, Estonia, Hungary, Norway, and the UK, welfare systems were persistently characterized as complex, burdensome and slow, demanding technical knowledge often beyond the reach of those facing crisis. This opacity forces claimants to rely heavily on informal support networks and supporting third-sector organisations. The administrative burdens go far beyond paperwork, manifesting as repeated humiliations where individuals must continuously justify their needs through invasive assessments and relentless verification. While digitalisation of benefit systems is often viewed as promising increased efficiency and may be experienced positively by people who have digital skills and access to appropriate devices and internet, it has often introduced new forms of exclusion for those lacking technological access or literacy, effectively adding digital barriers alongside bureaucratic ones.

The emotional toll of these systemic failures stands out as one of the report's most important findings. Participants described interactions with welfare systems that systematically erode dignity – disability assessments demanding physical exposure; caseworkers treating claimants as suspects rather than individuals in need. Psychological impacts include recurring narratives of shame, anxiety, and powerlessness, with many depicting welfare apparatuses as sources of trauma rather than support. Particularly stark are accounts of how the stress of navigating benefits worsens existing health conditions, creating a cruel paradox where systems designed to provide security instead generate further vulnerability and hardship.

Geographic and institutional inconsistencies exacerbate these problems, producing a “welfare lottery” where outcomes depend on the luck of the caseworker or regional office handling a claim. Positive exceptions – such as Spain's respectful in-home assessments or Scotland's rights-based approach – highlight the possibility of humane alternatives.
When individuals seeking support are persistently criminalised, or when disabled people are required to repeatedly substantiate their disabilities, these practices reflect not mere deficiencies in service delivery but fundamental failures in the foundational principles underpinning welfare systems. The emotional narratives presented in this report challenge prevailing political rhetoric that frames ‘welfare dependency’ as an individual failing, instead exposing how systemic structures perpetuate cycles of precarity.

Moving forward, the Welfare Experiences project will deepen its investigation through longitudinal qualitative fieldwork tracking twenty participants per country over six months to capture the cumulative impact of welfare interactions. This will be followed by the first comparative survey of 1,150 benefit claimants (200–250 per country). Together with ongoing collaboration with our co-production partners, these methods will build a robust evidence base to support co-created solutions with advocacy groups and diverse communities.

We aim to advocate for an experience-based, dignity-centred framework for welfare reform. Serving as both documentation and analysis, this report highlights the recurring shortcomings of welfare systems in upholding their foundational promises. As the research progresses, it urges policymakers to collaborate closely with people receiving benefits and to place lessons from lived welfare experiences at the heart of efforts to design and implement meaningful welfare reform. The stakes extend far beyond mere administrative adjustments and financial incentives, raising fundamental questions about whether benefits truly provide dignity, security and justice.