Qualitative methods for studying social security benefits: methodological reflections on an ongoing project

Dr Kate Summers

British Academy Postdoctoral Research Fellow,

Department of Methodology, LSE

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The British Academy

Outline

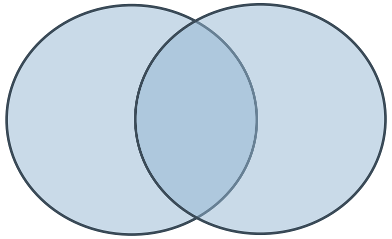
- Study motivation
- Study context
- Study design
- Two early insights
- Discussion points

Study motivation

Overall aim: To understand the experiences of working-age social security claimants with a (self-determined) long term health condition or disability.

Policy context.

- Trajectory and discourses of ‘welfare reform’.
- Lessons from the pandemic.
- Projected claimant caseload and economic context.



Methods context.

- Debates around ‘lived experience’.
- Lessons from the pandemic.
- Turn towards participation.
- Lessons from other disciplines.
- Inclusive methods.

Context: the UK working-age social security system

‘Legacy Benefits’:
- Jobseekers Allowance
- Employment and Support Allowance
- Income Support
- Housing Benefit
- Child Tax Credit
- Working Tax Credit

2.5 million on legacy benefits (end of 2022)

- **Disability Living Allowance**

Universal Credit

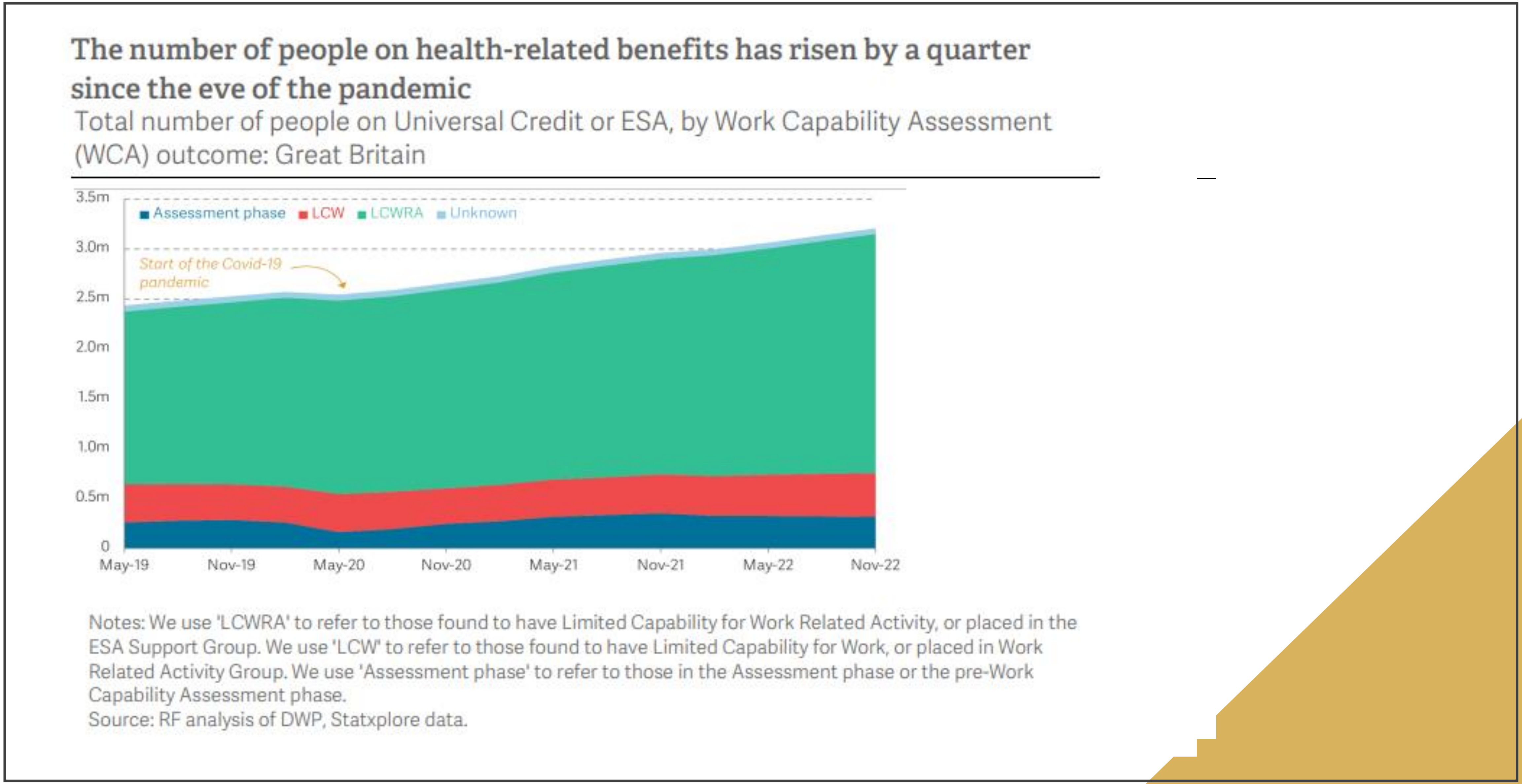
Standard allowance £393.45 / month
6.3 million claimants (December 2023)

- Contribution based (‘new style’) JSA
- Contribution base (‘new style’) ESA
- Local government support (e.g. council tax support; discretionary support)
- Child benefit
- **Personal Independence Payment (3.4 million cases w. entitlement Oct 2023)**

Aim of UC is “to **simplify** and **streamline** the benefits system for claimants and administrators, to **improve work incentives**, to **tackle poverty** among low income families, and to **reduce** the scope for **fraud and error**.”

DWP Stat Xplore; House of Commons Library Universal Credit Briefing Papers

Focus on claimants with a long-term health condition or disability



The number of people on health-related benefits has risen by a quarter since the eve of the pandemic

Total number of people on Universal Credit or ESA, by Work Capability Assessment (WCA) outcome: Great Britain

Notes: We use 'LCWRA' to refer to those found to have Limited Capability for Work Related Activity, or placed in the ESA Support Group. We use 'LCW' to refer to those found to have Limited Capability for Work, or placed in Work Related Activity Group. We use 'Assessment phase' to refer to those in the Assessment phase or the pre-Work Capability Assessment phase.

Source: RF analysis of DWP, Statxplore data.

Resolution Foundation (2023) Reassessing the Work Capability Assessment

Focus on claimants with a long-term health condition or disability

Department for Work & Pensions

Policy paper

Transforming Support: The Health and Disability White Paper

Updated 16 March 2023

Executive Summary

1. Our vision in this White Paper is to help more disabled people and people with health conditions to start, stay and succeed in work. With more than a million job vacancies and a rise in remote working triggered by the pandemic, today's labour market offers disabled people new working opportunities. By improving work incentives, we will enable more people to enjoy the financial benefits of a regular pay packet, as well as the positive impact on health and wellbeing for the individual and the wider benefits to society and the economy.

5. We know that the health and disability benefits system can itself be a barrier to employment because it focuses on what people cannot do, instead of what they can. The current assessment process means you need to be found to have limited capability for work and limited capability to prepare for work to get additional income-related support for a disability or health condition.

- 'Creeping conditionality' (Dwyer, 2004; Garthwaite, 2014; Baumberg Geiger, 2017)
- 'Work first' social security system (Dwyer and Wright, 2014; Andersen, 2020)
- Issues of adequacy (Edmiston et al., 2023)

DWP Official Statistics: UC Work Capability Assessment, April 2019 to September 2023; **Dwyer** (2004), 'Creeping Conditionality in the UK: From Welfare Rights to Conditional Entitlements?', Canadian Journal of Sociology 29:2; **Garthwaite** (2014), 'Fear of the Brown Envelope: Exploring Welfare Reform with Long-Term Sickness Benefits Recipients', Social Policy and Administration 48:7; **Baumberg Geiger** (2017) 'Benefits conditionality for disabled people: Stylized facts from a review of international evidence and practice', Journal of Poverty and Social Justice 25:2; **Dwyer and Wright** (2014), 'Universal Credit, ubiquitous conditionality and its implications for social citizenship', Journal of Poverty and Social Justice 22:1; **Andersen** (2020) 'Universal Credit, gender and unpaid childcare: Mothers' accounts of the new welfare conditionality regime', Critical Social Policy 40:3, **Edmiston et al.,** (2023), 'Building on broad support for better social security', IPPR Progressive Review 30:2

Why focus on 'lived experience'?

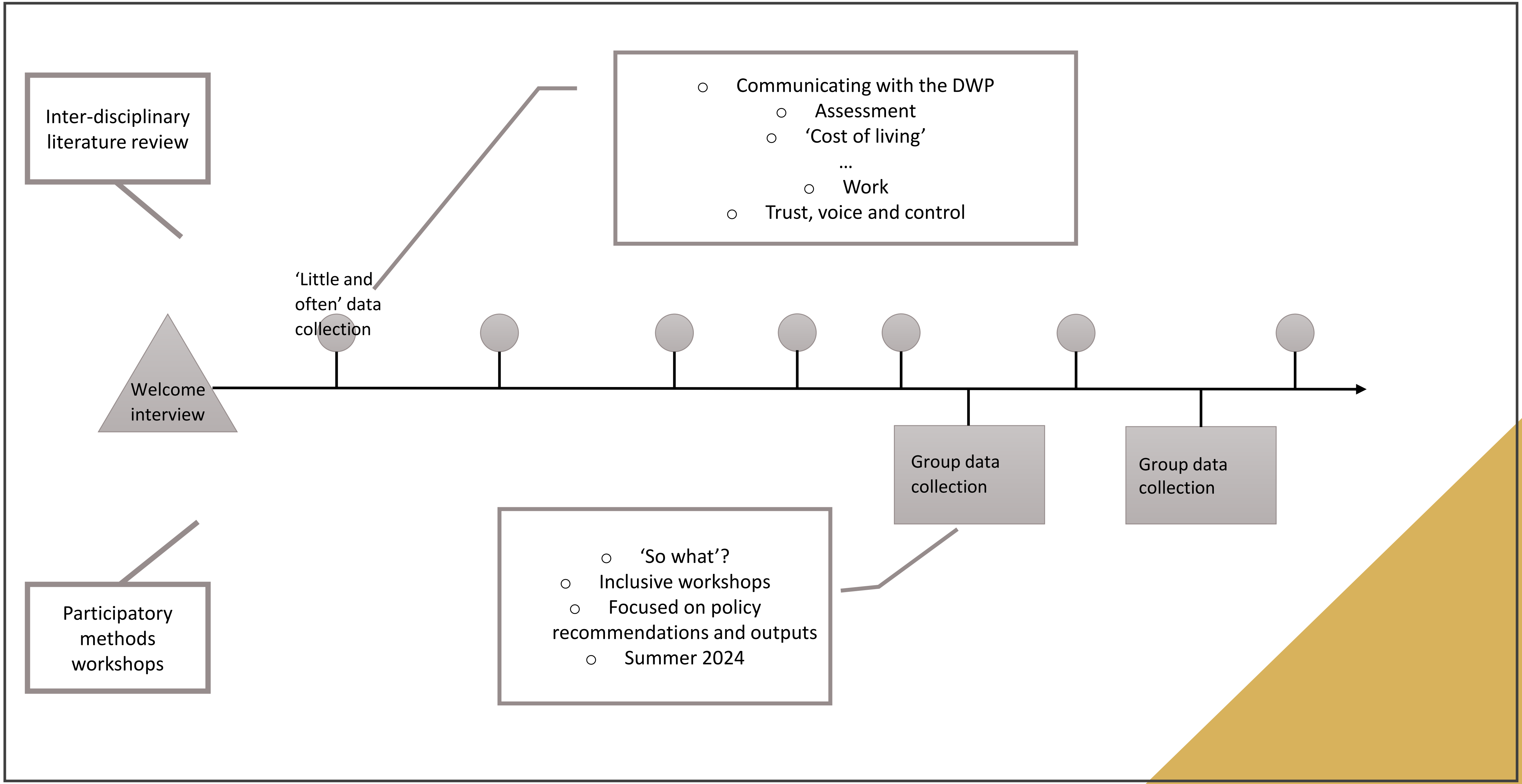
"...in social policy as well as related disciplines, **'lived experience' is used as a compelling basis of knowledge** or form of evidence, which is usually invoked **without exploration or clarification about what the term itself might mean** or imply." (McIntosh and Wright, 2018)

"Our primary claim is that the field of power for social security policymaking is so dominated by the state that social **security beneficiaries have fewer opportunities to forge power blocs which can extract claims from the state.** This is because the state is principally responsible for creating the practices that structure social security systems and has successfully managed to avoid the identification of any democratic deficit in the social security policy field – this marks the articulation of a very effective logic of equivalence unified against out of work beneficiaries of means-tested social security characterised as skivers." (Speed and Reeves, 2023)

- Ubiquity of in-depth interviews (e.g. WelCond project; WASD project).
- Turn towards participation (Patrick, 2020).
- Inter-disciplinary insights, esp. From health and international development. (Budworth, 2023; Kothari and Cooke, 2001)

McIntosh and Wright (2019), 'Exploring what the notion of 'lived experience' offer for social policy analysis', Journal of Social Policy 48:3; **Speed and Reeves** (2023), 'Why is lived experience absent from social security policymaking?', Journal of Social Policy; **Patrick** (2020), 'Unsettling the anti-welfare commonsense: The potential in participatory research with people living in poverty', Journal of Social Policy 49:2; **Budworth** (2023), 'Care, comfort, and capacity: The importance of being flexible in research with disabled and chronically ill people', Qualitative Research in Health 4; **Kothari and Cooke** (eds.) (2001), *Participation: The New Tyranny?,* Zed Books.

… the study design



Inter-disciplinary literature review

Participatory methods workshops

Welcome interview

'Little and often' data collection

- Communicating with the DWP
- Assessment
- 'Cost of living'
- …
- Work
- Trust, voice and control

Group data collection

Group data collection

- 'So what'?
- Inclusive workshops
- Focused on policy recommendations and outputs
- Summer 2024

		Age	From	Benefits	Health Condition (self-described)	Summary of how health affects their day to day living at welcome interview	Summary of how they are doing financially at welcome interview
1	Jessie	30s	Kent	PIP, ESA, HB, CTC, CB	MS, ADHD	A great deal	Doing alright
2	Mary	50s	Stockport	PIP, ESA, UC	ME, Long Covid	A great deal	Finding it quite difficult
3	Lizzie	40s	London	PIP, UC	Mixed depressive orders, osteoarthritis	A great deal	Finding it quite difficult
4	John	50s	Teeside	PIP, UC	Asthma, diabetes, thyroid cancer	A great deal	Finding it quite difficult
5	Hannah	30s	London	PIP, UC	Anxiety, depression	To some extent	Just about getting by
6	Bobby	30s	Manchester	ESA	Anxiety, depression, autism	A great deal	Finding it quite difficult
7	Harry	50s	Cardiff	PIP, UC	Osteoarthritis	A great deal	Just about getting by
8	Amy	50s	Lancashire	ESA, PIP, HB	Fibromyalgia, Rheumatoid arthritis, copd	A great deal	A great deal
9	Rachel	40s	Manchester	UC	Bipolar type 2, anxiety	A great deal	Just about getting by
10	Robert	40s	Hertfordshire	PIP, UC	Heart condition AML, lung lobectomy, epilepsy	A great deal	Finding it quite difficult
11	William	30s	Liverpool	PIP	Quadriplegia, glaucoma	A great deal	Just about getting by
12	Graham	40s	Manchester	DLA, UC	VBI symptoms, severe headaches, back pain	A great deal	Finding it quite difficult
13	Tom	20s	Leicester	UC	Severe chronic depression, generalised anxiety disorder	A great deal	Finding it quite difficult
14	Maria	30s	Swindon	PIP, UC, CB	Bipolar, fibromyalgia	A great deal	Finding it quite difficult
15	Ellen	30s	Cardiff	PIP, UC, Carers Allowance	Anxiety and depression, fibromyalgia, severe asthma	A great deal	Finding it quite difficult
16	Emily	40s	London	PIP, UC	Fibromyalgia, major depressive disorder	A great deal	Finding it quite difficult
17	Lily	50s	Brighton	PIP, UC	Rheumatoid arthritis, gastropareses, adhd, ptsd, diabetes, adrenal insufficiency	A great deal	Finding it quite difficult
18	Frank	30s	Shropshire	PIP, UC	Social anxiety, OCD, depression, previous psychosis	To some extent	Doing alright
19	Lucia	30s	London	PIP, UC	Sickle cell, asthma	A great deal	Finding it quite difficult
20	Claudia	20s	London	PIP, UC	Electric wheelchair user (health conditions known but not disclosed here)	A great deal	Just about getting by

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Early insight 1 – prompt format

Hello XXX,

This is prompt 1 for our theme *cost of living and benefit payments*.

How would you say you are managing financially at the moment? And how does this relate to the benefits you currently receive?

Please give examples if you are able to.

You can reply in any way you would like: this could be email; voicenote; whatsapp; photos; the choice is yours.

Use XXX if replying by phone.

Please spend up to 15 minutes on this, at a time that suits you over the next week.

Thank you,

Kate

Hello XXX,

This is prompt 2 for our theme *cost of living and benefit payments.*

Please could you tell me more about any extra costs related to your health condition and/ or disability?

How do these costs relate to the benefits you currently receive?

You can reply in any way you would like: this could be email; voicenote; whatsapp; photos; the choice is yours.

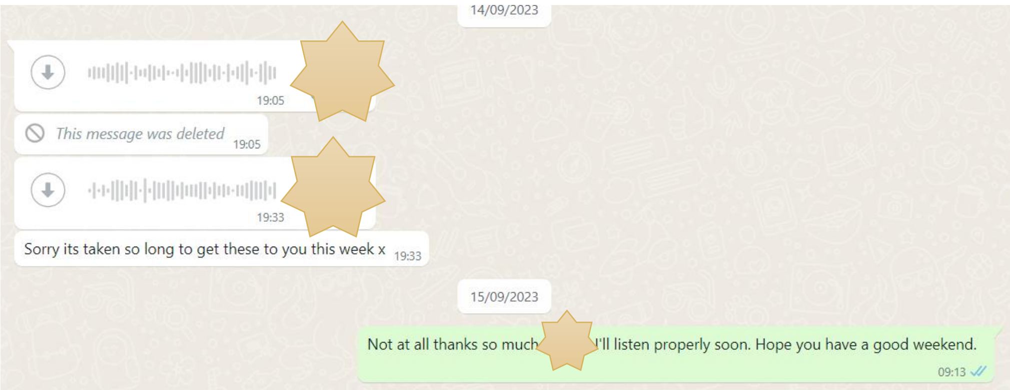
Use XXX if replying by phone.

Please spend up to 15 minutes on this, at a time that suits you over the next week.

Thank you,

Kate

Early insight 1 – prompt format



14/09/2023

19:05 [redacted]

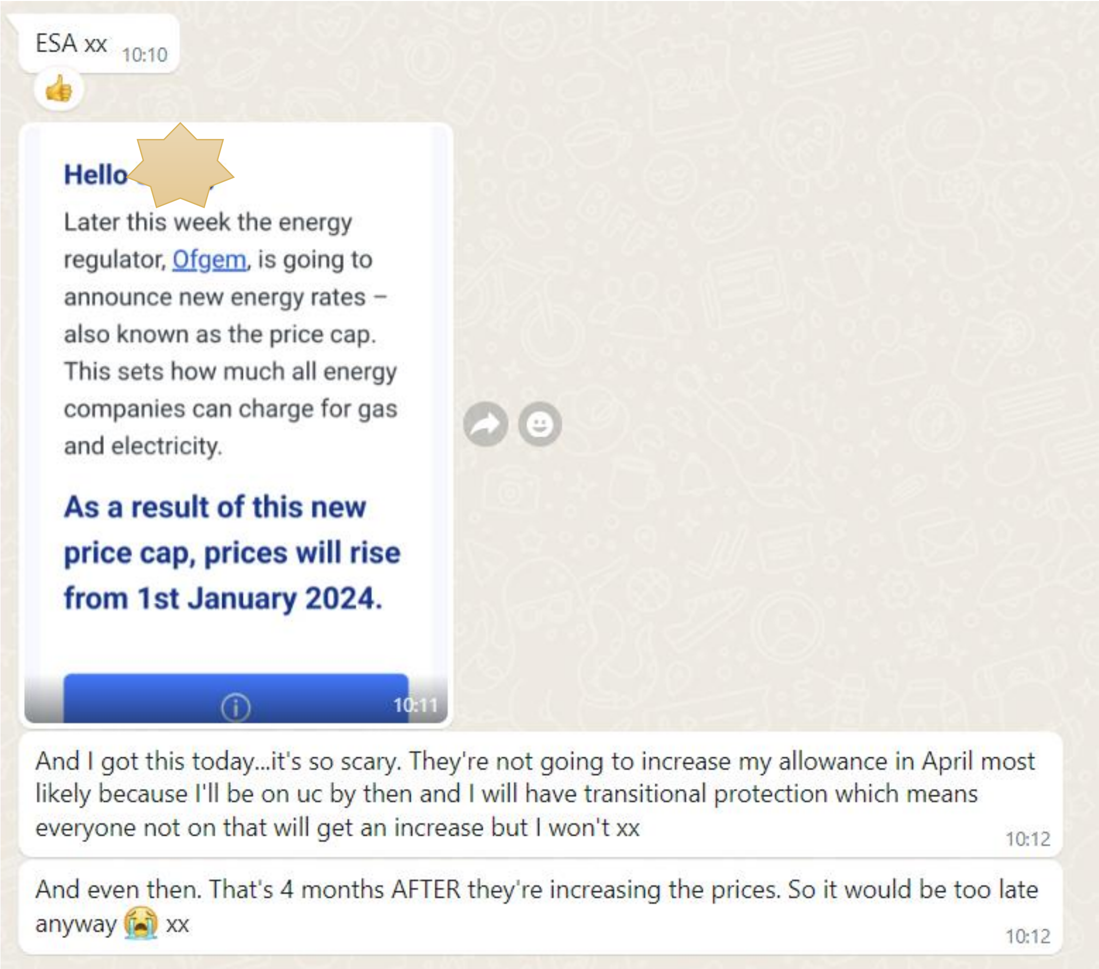
This message was deleted 19:05

19:33 [redacted]

Sorry its taken so long to get these to you this week x 19:33

15/09/2023

Not at all thanks so much [redacted] I'll listen properly soon. Hope you have a good weekend. 09:13



ESA xx 10:10

Hello [redacted]

Later this week the energy regulator, Ofgem, is going to announce new energy rates – also known as the price cap. This sets how much all energy companies can charge for gas and electricity.

As a result of this new price cap, prices will rise from 1st January 2024.

10:11

And I got this today...it's so scary. They're not going to increase my allowance in April most likely because I'll be on uc by then and I will have transitional protection which means everyone not on that will get an increase but I won't xx 10:12

And even then. That's 4 months AFTER they're increasing the prices. So it would be too late anyway 😭 xx 10:12

Early insight 1 – prompt format

I did a picture to illustrate .. I’m completely going under financially .. healthy food is too expensive.. my type 2 diabetes is really unstable as I have to eat cheap food like white bread and other high carb foods. I was going to a food bank but it closed last week as they don’t have enough food. I’m on the waiting list but there is a long wait.

I can’t afford to heat my home and my flat is freezing and damp. I had to run a dehumidifier and that costs money.

I get really stiff and immobile when it is cold as I have Rheumatoid Arthritis. I can’t afford baths any more, which help my mobility and I take cold showers now instead.

I had to get a private prescription for medical cannabis as it was dangerous to take opioids because of a previous bowel perforation, but it costs £250 a month. I am terrified about not being able to get my medication, as I can’t function without it.

I had to stop my therapy as I could not afford it and my mental health has suffered.

I desperately need new clothes as I’ve lost weight and they all fall off me, but I can’t even afford a new pair of leggings.

I am panicking about not having any money for vet bills for my cat. She is elderly and I have nothing saved up.

I desperately need to get £2000 for a new roof and my neighbour is threatening to sue me.

I can’t afford to top up my motability car with much electricity, which means I rarely go out unless I have a medical appointment,

I need at least £400 a month more than I get on disability benefits. The cost of living has gone up but my care contribution from the council has not gone down.

‘Lily’ Cost of Living Prompt 1

Hi, apologies, for finishing this late.. I had a crisis on tuesday, Universal credit stopped my benefits on the day they were due, with no warning, no message or email. It was quite a shock. They have reinstated them this Friday, and have now closed the fraud investigation as they say I was completely above board, but it was brutal for them to stop them on Tuesday. I only realised today that I was half way through your questions, so please accept my apology!

Here is the full version:

1: I have complex diatary needs as I need to avoid gluten, dairy and fat due to my bowel condition and and reduce carbs due to Type 2 diabetes. I also have to have high protein so my food bill is about £105 a week. £420 a month

The only safe exercise is swimming and the only pool that has accessible steps is £180 a month, but I need it as I am so stiff due to rheumatoid arthritis so I need to swim. I have to have the heating on as I am so stiff and in pain if it is cold . I also have equipment such as CPAP MACHINE, and electric bed. I have incontinance so need put the washing machine on most days. I run a dishwasher as I can't stand to wash up. My energy bills are £170 a month , summer and winter. I also need hot baths to help mobility. I have an old electric bed that breaks a lot, it is £195 call out charge to fix it . It has broke twice this year. I have to use incontinant pads and incontinant pants. I spend around £200 a year . I buy a lot of medicines and natural remedies . I buy things like Melatonin, and herb tinctures to help my liver , digestion and for anxiety . I spend about £20 a month. My private medical cannabis prescription costs me £200 a year clinic fees and £160 a month in medication.

I have 2 PAs/ Carers and have to pay £88 a month contribution. I have a Motability car and it costs me £15 a week to charge it, plus £10 a year parking permit. I have to have a blue light blocker on my glasses due to an eye condition and have to get new glasses every year . I also need near and far glasses plus prescription sunglasses . It costs about £200 a year. I have low cost shiatsu twice a month £10. I have to use chemical free fragrance free beauty products and cleaning products.. I have no idea how much I spend on all that but it is a lot. There are always other one off disability costs, on top if these regular ones, such as heating pads, painkillers, eye drops.

I get roughly £1100 month in benefits. I have Dyscalculia, so can't add it up, but it's a lot of money that I spend on my health. Being chronically ill and disabled is cripplingly expensive, unfortunately,

I used to be able to just about cope up until the welfare reform, and now I get a lot less benefits than I used to on esa, as universal credit cut the severe disablement tax and single person disabled tax, which I used to qualify for.

'Lily' Cost of Living Prompt 2

Early insight 2

Hi Kate,

Happy new year to you too, I hope your 2024 is full of great things.

I'm still very under the weather unfortunately. I think the last time we spoke I'd had a bad relapse. That has continued but I also developed flu over Christmas along with laryngitis. It's taking a while to shake it off so I'm quite limited at the moment.

Yes please contact me when you need more input later in the year and if I'm well enough I will absolutely tale part.

As far as benefits experience goes, at the moment it's not going well either. 2 things have happened -

a) my PIP review was completed and returned last June, but has still not been looked at. When I spoke to the DWP (lengthy wait in a queue first as usual) I was told they are around 7 months behind but that PIP would be automatically extended for a year or until the review was completed, whichever came sooner.

It's not good because PIP review in itself is an incredibly anxious time. From speaking to others like me, many of them have had their points downgraded or the award removed altogether, even though they are no better. Listening to the government's talk about getting sick and disabled people back to work is quite worrying because if I could work right now, I absolutely would be. I had a job I enjoyed with a decent income. My income now is entirely benefits and it's a massive struggle. Being hit with a government stick will change nothing about my ability to work, it will just cause me more stress which is also a trigger for making my condition worse, ME/Long Covid and Bipolar/Generalised Anxiety Disorder. It would be nice if the government acknowledged that lack of PPE in Care meant many of us caught Covid at work in the first place and that if it wasn't for that we would still actually be working and enjoying a much better income.

Also, other assistance I receive is contingent on my PIP award. Blue Badge, Nimbus Access card which helps me to get assistance at places I visit, etc. So not having my PIP reviewed on time has an impact on being able to renew these, which is even more stress and makes life difficult in the meantime.

Early insight 2

b) I was sent a text message from DWP in December saying they had received my enquiry about my ESA. However I hadn't sent them an enquiry about ESA so that was a bit of a mystery.

I then received a letter from XXX Council saying that as my benefits had just changed they had reviewed my council tax discount and it hadn't changed. I then rang DWP (lengthy queue as usual) and asked them what had changed to prompt both the text and the letter from the council. They said they weren't aware of anything and I should ring the council. I explained that the council were obviously reacting to a notification they had received from DWP so there was no point speaking to them as they would just refer me back to the DWP. This is while I'm feeling really poorly so could have done without spending 45 minutes in a queue to speak to someone who didn't have a clue. Even with brain fog I still felt more intelligent than the person on the phone!

A letter arrived a few weeks ago from the DWP saying that due to recent changes in my circumstances (what changes? Nothing has changed) they have reviewed my ESA and this has been adjusted. Then it gave figures for the past 3 years. I have absolutely no idea what is going on, and I am currently feeling far too unwell to do battle with the DWP phone agents to find out, on the basis that they probably won't be able to tell me and the hour I'd spent on the phone would use up the majority of my very limited energy for the day with nothing to show for it.

So, right at the moment, it feels like the DWP is just causing complications all by itself, with no input from me at all. Unfortunately the complications impact me and I have absolutely no control over resolving this.

I hope that rant is helpful in some way!

Take care of yourself and I'll speak with you again when you're ready for the next part of your project.

Kind regards

‘Mary’

Next steps:

- ➢ Feeding forwards into remaining prompts
- ➢ Group workshops
- ➢ Analysis and writing up

Some methodological take aways/ discussion points

- ➢Developing practice over multiple projects and years. Ethical implications; participants as collateral?
- ➢The role of the researcher within the participatory turn in social policy? Beyond giving voice vs. stepping out of the way.
- ➢The role of ‘bendable’ (Budworth, 2023) research (for both researcher and participants). Opportunities for this within existing structures.

Thank you

Kate

k.summers@lse.ac.uk