

# Personal Independence Payments (PIP) for individuals with Narcolepsy

Ruth Adeyeye<sup>1,3</sup>, Helen Strongman<sup>1,2</sup>, Martina Sykorova<sup>1</sup>,

<sup>1</sup> London School of Hygiene & Tropical Medicine    <sup>2</sup> Narcolepsy UK  
<sup>3</sup> Health Data Research UK



## Background

**Narcolepsy** is a chronic neurological disorder affecting around 30,000 people in the UK, causing excessive daytime sleepiness and sudden sleep episodes. These symptoms severely impact quality of life. **Personal Independence Payment (PIP)** is a UK government benefit designed to help individuals with long-term health conditions manage the additional costs associated with their disability. However, the PIP application process is complex and challenging.

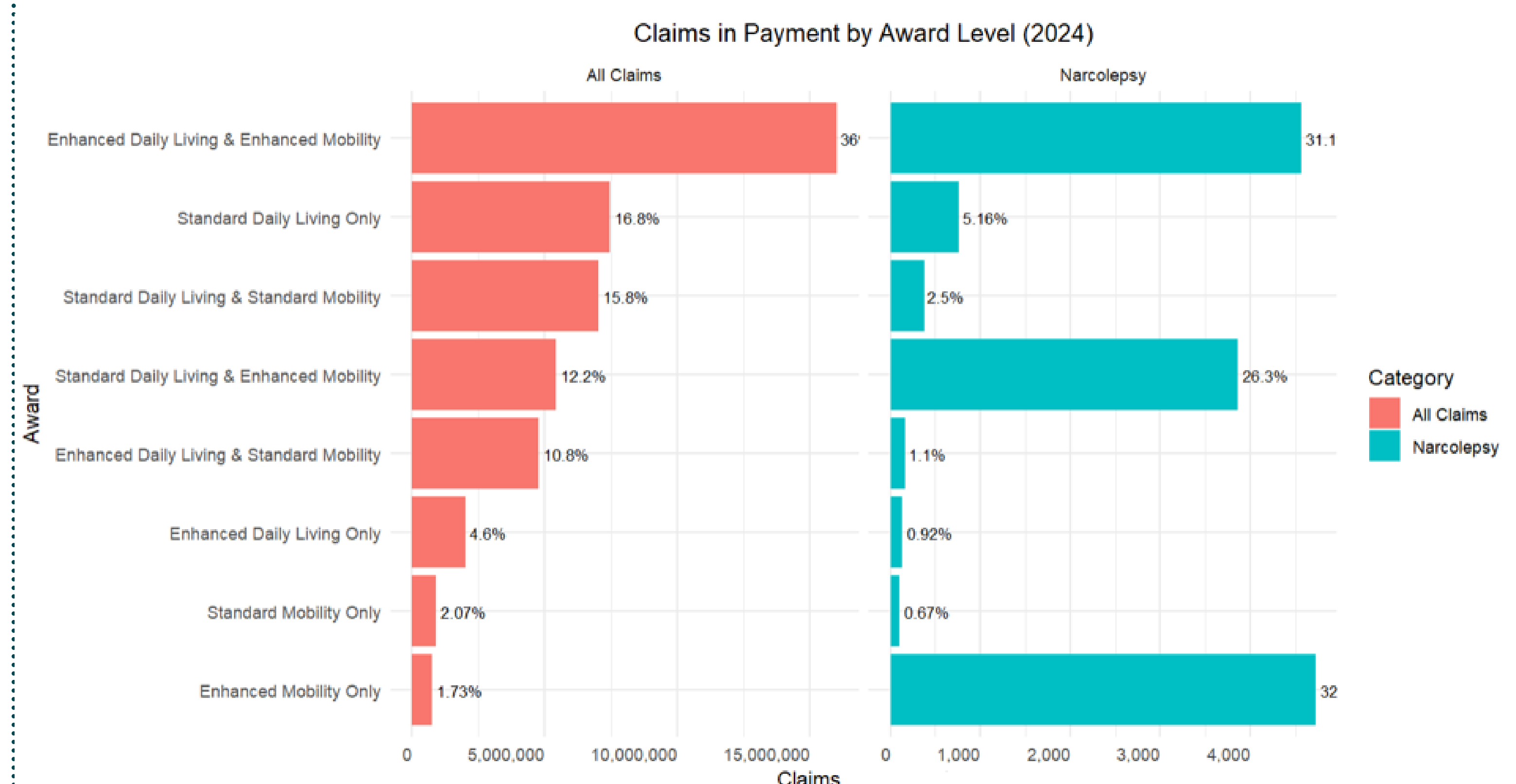
Currently, little is known about the prevalence of PIP claims among people with narcolepsy in the UK, nor about the success rates and timelines of these applications. Understanding these aspects is crucial for improving the support available to individuals with narcolepsy.

## Methods

**Data source:** Department for Work and Pensions: Personal Independence Payment: Official Statistics to October 2023.

**Study population :** People registered for Personal Independence Payments (PIP) between 01/2013 and 04/2024.

## PIP Entitlements by Local Authority



**Figure 3: Distribution of PIP Award Levels for All Disabilities vs. Narcolepsy.** This bar chart compares the distribution of PIP entitlement levels between all disabilities and narcolepsy. Awards are categorised into two types: *daily living and mobility*, with three levels: nil (no award), standard, and enhanced.

	Standard	Enhanced
Daily living	£72.65	£108.55
Mobility	£28.70	£75.75

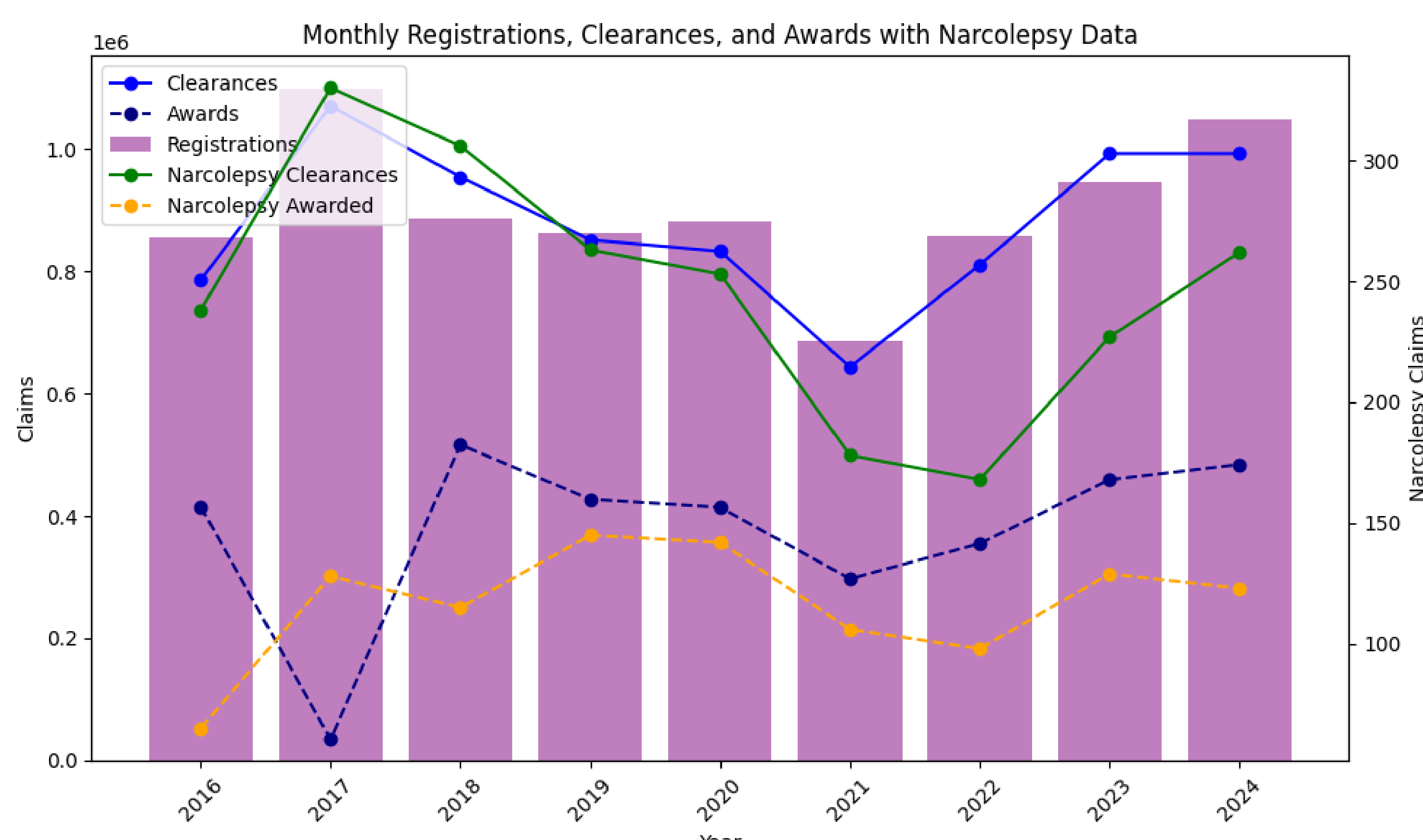
## Limitations

- **Appeals Information:** The dataset lacks full details on Mandatory Reconsiderations and Tribunal Appeals, limiting insight into the decision-making process.
- **Person-Level Tracking:** Absence of individual-level data makes it difficult to track outcomes over time.
- **Insufficient Metadata:** Limited metadata limits our understanding of variable meanings and data collection methods.
- **Narcolepsy Registration Gaps:** The number of individuals with narcolepsy that registered is not available.
- **Process Duration Unknown.**
- **No Data on Socio-economic Status.**
- **Delayed Ethics Approval** (Narcolepsy UK data)

## Results

	Narcolepsy (%)		All Disabilities (%)	
<b>Total Registrations</b>	Not Available		1,049,083	
<b>Total Clearances</b>	262		992,487	
<b>Awarded</b>	123 (46.90%)		484232 (48.80%)	
<b>Financial Award</b>	£122.89		£126.94	
<b>Gender</b>	Male	40.4%	Male	45.3%
	Female	59.6%	Female	54.7%
<b>Mode Age group</b>	45-54 (24.1%)		55-64 (26.93%)	
<b>Mandatory Reconsiderations Registrations</b>	143		315,424	
<b>Mandatory Reconsiderations Clearances</b>	137		294422	
<b>Mandatory Reconsiderations Outcomes</b>	Award Changed – 39 (28.7%)		Award Changed – 71428 (24.3%)	
<b>Tribunal Registrations</b>	Not Available		Not Available	
<b>Tribunal Outcomes</b>	Not Available		Not Available	

**Table 1: Results.** This table compares key metrics between narcolepsy and all disabilities.



**Figure 1: Trends in PIP Registrations, Clearances, and Awards for All Disabilities vs. Narcolepsy.** This figure illustrates the annual trends in PIP registrations, clearances, and awards for all disabilities compared to narcolepsy-specific claims. The x-axis represents the years, with two scales: the left for all claims and the right for narcolepsy claims.

## Conclusion

- The database, while offering valuable insights, **has notable gaps** that hinder a comprehensive analysis.
- Addressing these limitations will improve our understanding and the effectiveness of PIP entitlements.
- Future work could analyse the supplementary data from **Narcolepsy UK**.

<sup>1</sup> Personal independence payment: Official statistics to October 2023 (2023) GOV.UK. Available at: <https://www.gov.uk/government/statistics/personal-independence-payment-statistics-to-october-2023/personal-independence-payment-official-statistics-to-october-2023> (Accessed: 20 August 2024).

<sup>2</sup> Local Authority districts (May 2022) boundaries UK BFE (v3) (2022) Open Geography Portal. Available at: <https://geoportal.statistics.gov.uk/datasets/ons::local-authority-districts-may-2022-boundaries-uk-bfe-v3-2/explore?location=51.460062%2C-0.211512%2C7.24> (Accessed: 20 August 2024).

<sup>3</sup> Estimates of the population for the UK, England, Wales, Scotland, and Northern Ireland - Office for National Statistics. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland> (Accessed: 20 August 2024).

<sup>4</sup> Justice, M. of (2024) Tribunals Statistics Quarterly: January to March 2024, GOV.UK. Available at: <https://www.gov.uk/government/statistics/tribunals-statistics-quarterly-january-to-march-2024> (Accessed: 20 August 2024).