PCR207

Real-World Socioeconomic Burden and Health-Related Quality of Life (HRQoL) For Patients Living With Chronic Inflammatory Demyelinating Polyradiculoneuropathy (CIDP) in The UK: Results From an Online Patient Survey

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INTRODUCTION

CIDP is a rare, immune-mediated neuropathy characterised by progressive weakness, sensory disturbance and fatigue.[1–3] Inflammatory Neuropathies UK estimates that up to 650 people are diagnosed each year in the United Kingdom.[4] Despite the clinical burden, there are no NICE technology appraisal recommendations for CIDP. Standard therapies benefit many patients; the literature estimates that ~25% of CIDP patients do not respond to evidence-based first-line therapy with steroids, plasma exchange and intravenous immunoglobulins.[5] A comprehensive understanding of the socioeconomic impact and HRQoL among CIDP patients in the United Kingdom has been lacking.

OBJECTIVE

The overarching objective is to understand the socioeconomic burden and HRQoL of people living with CIDP. To address this the survey aimed to:

- Quantify patient-reported symptom burden
- Measure HRQoL and derive utility values using the EuroQoL 5 dimensions 5 levels (EQ-5D-5L) and EuroQoL visual analogue scale (EQ-VAS)
- Explore treatment preferences and satisfaction with current therapies

METHODS

- **Design and setting** – Cross-sectional, web-based survey fielded between the 14 April and 18 May 2025 in collaboration with Inflammatory Neuropathies UK
- **Participants** – Adults (≥18 years) with a self-reported confirmed CIDP diagnosis
- **Variables** – Survey variables included demographics, diagnostic history, disease severity, current therapy, treatment satisfaction, patient HRQoL (EQ-5D-5L and EQ-VAS), work impact, out-of-pocket expenses, travel burden and care provision
- **Analysis** – All quantitative variables were summarised using descriptive statistics. Open-text responses were analysed qualitatively using thematic analysis

RESULTS

A CIDP Patient cohort experiencing diagnostic uncertainty

63 patients

- The patient cohort was evenly split between sexes (**50.8% male, 49.2% female**)
- **77.8%** aged **>55 years**, with **58.7% retired**
- **49.2%** experienced **≥ 1 prior misdiagnosis** (most often Guillain–Barré syndrome)
- **34.9% waited 3-6 months** and **17.4% waited ≥ 3 years for their diagnosis**

CIDP Patients report poor limb function, lower than normal HRQoL, and fear of symptoms worsening

EQ-VAS and EQ-5D-5L were both below UK population norms*[6,7]

EQ-5D-5L
0.595 ± 0.234 (SD)

EQ-VAS
56.0±20.1 (SD)

- **Only 15.9% reported** normal hand and arm function
- **12.7% reported** that they usually use a wheelchair outdoors
- The most frequently reported concern by patients was **possibility of symptoms returning or worsening**: 30.0% (n = 19) "often" and 37.0% (n = 23) "always" worried about this

CIDP Patients report early workforce exit, absenteeism and personal costs

- Among employed respondents (n = 15) **absenteeism averaged 25.4%**
- Four patients had **left work** a **median 6.5 years earlier** than planned due to CIDP
- Over the counter medicines cost £68 a month on average, physiotherapy £800 a month (range £1–£5,000) and travel to CIDP appointments each month £65
- **72.3% of patients receiving care** reported relying on unpaid care mostly by partners

CIDP Treatment relies on hospital IVIg, with concerns around convenience and control

49 patients reported current treatment

Current treatment (n = 49)	Number of patients
Immunoglobulin	37 (75.5%)
Intravenous immunoglobulin (IVIg)	30 (61.2%)
Subcutaneous immunoglobulin (SCIg)	7 (14.3%)
Immunosuppressant medicines	13 (26.5%)
Steroid tablets	12 (24.5%)
Other (steroid injections, plasma exchange, propranolol, rituximab, non-steroidal anti-inflammatory drugs, gabapentin)	6 (12.0%)

- Patients reported that 96.7% of IVIg infusions were delivered in a hospital setting
- IVIg users most frequently cited concerns about:
  - The frequency of infusions
  - The location of infusions
  - Poor symptom control
- 28.5% of patients did not report satisfaction with treatment: 8.1% (n = 4) were dissatisfied and 20.4% (n = 10) were neutral

Direct Patient Quotes Reveal the Daily and Emotional Toll of living with CIDP

"With my IVIg treatment, your ability to do general things declines when it gets closer to the next treatment and for a couple of days after, so it's like living your life on a rollercoaster between neuropathy pain, exhaustion and good days."

"My whole world changed overnight. From being a fit active sociable 64-year-old I became an immobile dependent person living with constant pain"

"I worry that I may not be able to continue working in the job that I love"

"CIDP robs you of your livelihood, independence, energy and at times enthusiasm for life… it imposes so many life-limiting restrictions upon you."

CONCLUSIONS

Patients living with CIDP in the UK carry a multifaceted burden that extends well beyond neurological symptoms and remains insufficiently addressed by current care pathways.

- **Patient anxiety around living with CIDP** – Prolonged delays and frequent misdiagnosis (often as Guillain–Barré syndrome) foster uncertainty and persistent anxiety in patients. Patients also expressed worries about their future of living with CIDP, including concerns about potential symptom worsening.
- **Burden on HRQoL**– HRQoL deficits exist compared to UK population norms* as well as self-reported pervasive fatigue that reshapes the daily life of CIDP patients.
- **Treatment limitations** – Hospital-based IVIg predominates, yet its frequency and travel demands leave some patients dissatisfied, underscoring the need for more convenient treatment options.
- **Socioeconomic and caregiving impact** – Early workforce exit (median 6.5 years), out-of-pocket costs for medicines, therapy and travel, and reliance on informal care (primarily spouses) create a substantial burden.

Together these results **provide a structured snapshot of the CIDP patient experience in the UK** and help to characterise the **ongoing burden associated with living with and managing the condition**.

Addressing the outlined areas of burden through clearer communication, flexible treatment planning, improved access to support services and alternative treatment options would represent **meaningful steps towards improving care**.

These efforts should **also align with government priorities** to deliver care closer to home, including the potential need for home nursing support.[8]

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*EQ-5D-5L scores were lower than age-matched norms (matched to the survey's most prevalent age bracket) reported by McNamara 2023.; EQ-VAS scores were compared against a non-age-matched UK average.

The patient survey and the creation of this poster was sponsored by argenx. Poster contents developed by Decisive Consulting, a Herspiegel Company.

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