

# Validation of Prevalence and Incidence Rates for Six Different Diseases Using Livingstone: An Online, Automated Analytical Platform



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## BACKGROUND & AIMS

- Incidence and prevalence are common metrics characterising the epidemiology of a disease.
- Both measures are essential to enable healthcare systems and organisations to plan service provision. They must therefore be accurate and trustworthy.
- Livingstone is an automated analytical platform that enables the user to define cohorts from real-world data and generate reproducible epidemiology reports.
- In this study, we estimated the incidence and prevalence of six neurological conditions using Livingstone and compared these with results from a routine database study by Carey et al (1).

## METHODS

- Both Livingstone and Carey et al used data from the Clinical Practice Research Database (CPRD) to describe the epidemiology of inflammatory myopathy, muscular dystrophy (MD), Charcot-Marie-Tooth disease, Guillain-Barré syndrome, myasthenia gravis, and motor neurone disease (MND).
- CPRD contains longitudinal anonymised data collected in a non-interventional manner from practice management systems at participating practices in the UK.
- CPRD comprises two databases, CPRD GOLD and Aurum. The analyses by Livingstone and Carey et al combined both databases. Practices that migrated from GOLD, were removed to avoid any duplication of cases.
- The study population comprised all patients of acceptable research quality as defined by CPRD.
- Using the code lists provided by Carey et al, Livingstone generated cohorts for the six conditions and estimated prevalence and incidence.
- Point prevalence was defined as the proportion of the population diagnosed with the condition prior to the midpoint of a given calendar year. All conditions were considered lifelong from first incident recording.
- The denominator population comprised all patients whose registration period overlapped the midpoint.
- Incidence was defined as the number of patients having a first diagnosis record of a condition in a calendar year. To approximate a true incident population, patients were required to have minimum 90 days' registration prior to the diagnosis being recorded.
- Denominator time comprised the total registration period for all patients in the dataset having at least 90 days' registration.
- Estimates for annual incidence and prevalence 2004–19 of the six conditions were compared individually and together.
- Lin's concordance coefficient (CCC) was used to measure the concordance between estimates from Livingstone and Carey et al for each condition and overall, by year.
- This study has received CPRD Research Data Governance approval (22\_001781) & (22\_002001).

## RESULTS

### Prevalence and Incidence

- In the last year of the analysis (2019) the prevalence of the conditions ranged from 12.30 to 39.98 per 100,000 persons (Table 1).
- The incidence of the conditions ranged from 1.43 to 3.32 per 100,000 person years (Table 1).

Table 1: Livingstone estimates for prevalence and incidence of the six conditions.

Condition	Livingstone Estimate	
	Prevalence	Incidence
Guillain-Barré syndrome	39.98	1.63
Charcot-Marie-Tooth disease	27.70	1.57
Inflammatory myopathy	24.50	1.43
Myasthenia gravis	32.90	2.52
Motor neurone disease	12.30	3.32
Muscular dystrophy	31.10	1.58

### Overall Prevalence Concordance

- The overall CCC for the Livingstone-estimated prevalence of the six conditions together was 0.99 (95% CI: 0.99 – 0.99) showing a substantial strength of agreement (2) (Figure 1).

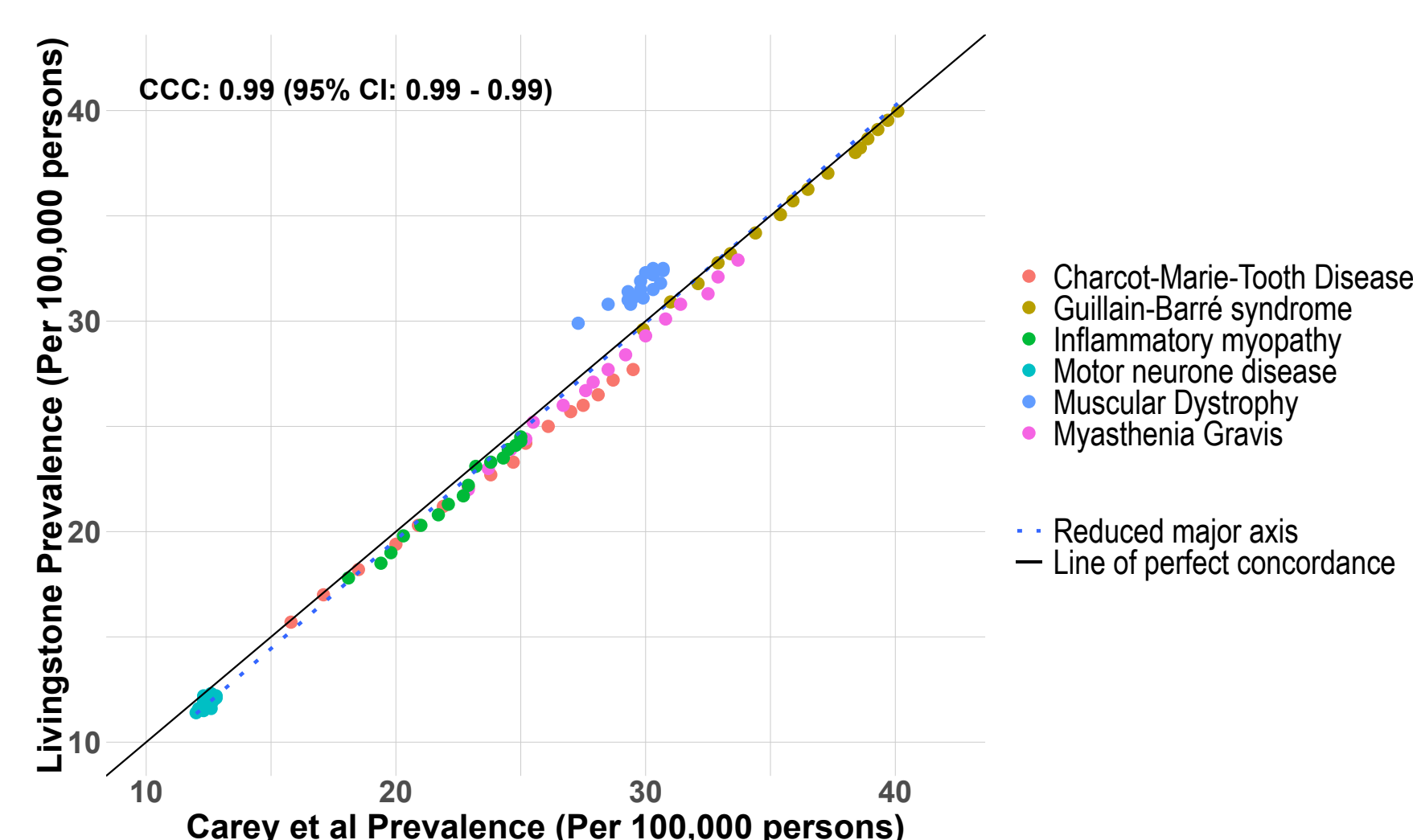


Figure 1: Comparison of prevalence estimates between Livingstone and Carey et al.

### Condition-Specific Prevalence Concordance

- The CCC of Guillain-Barré syndrome, Charcot-Marie-Tooth disease, inflammatory myopathy, and myasthenia gravis were 0.95 or above, showing a substantial strength of agreement.
- The CCC of MND and MD were 0.20 (0.02–0.37) and 0.24 (0.08–0.38) respectively. This was the lowest concordance with a poor strength of agreement (Table 2).
- Figure 2 shows the comparison between estimates by Livingstone and Carey et al split by condition.

Table 2: Prevalence concordance correlation coefficient split by condition.

Condition	Concordance correlation coefficient (CCC)	95% Confidence Interval
Guillain-Barré syndrome	1.00	(0.99 – 1.00)
Charcot-Marie-Tooth disease	0.96	(0.92 – 0.98)
Inflammatory myopathy	0.95	(0.89 – 0.98)
Myasthenia gravis	0.97	(0.94 – 0.99)
Motor neurone disease	0.20	(0.02 – 0.37)
Muscular dystrophy	0.24	(0.08 – 0.38)

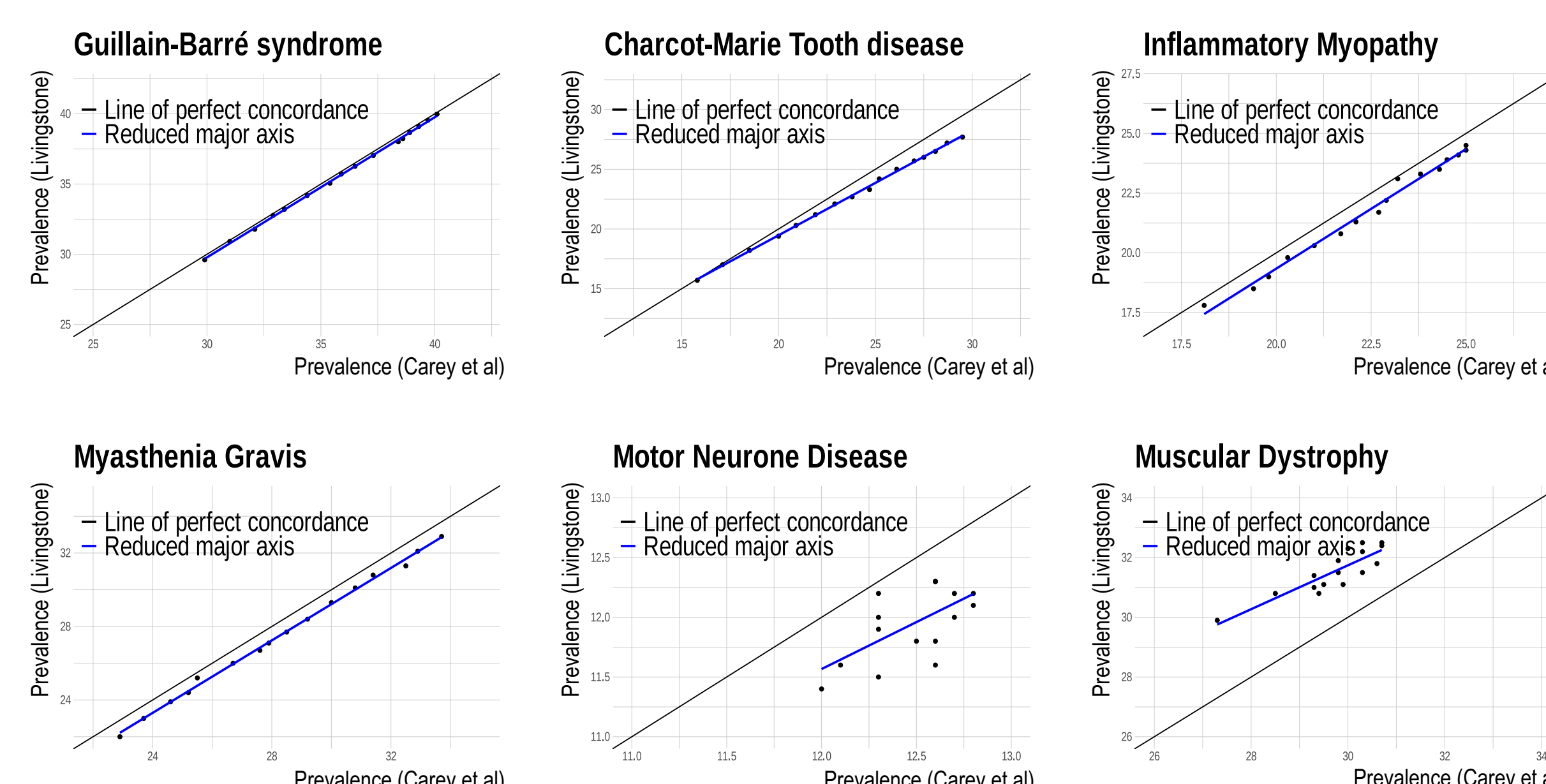


Figure 2: Comparison of prevalence estimates between Livingstone and Carey et al split by condition.

### Overall Incidence Concordance

- The overall CCC for the Livingstone-estimated incidence of the six conditions together was 0.97 (0.97–0.98) showing a substantial strength of agreement (Figure 3).

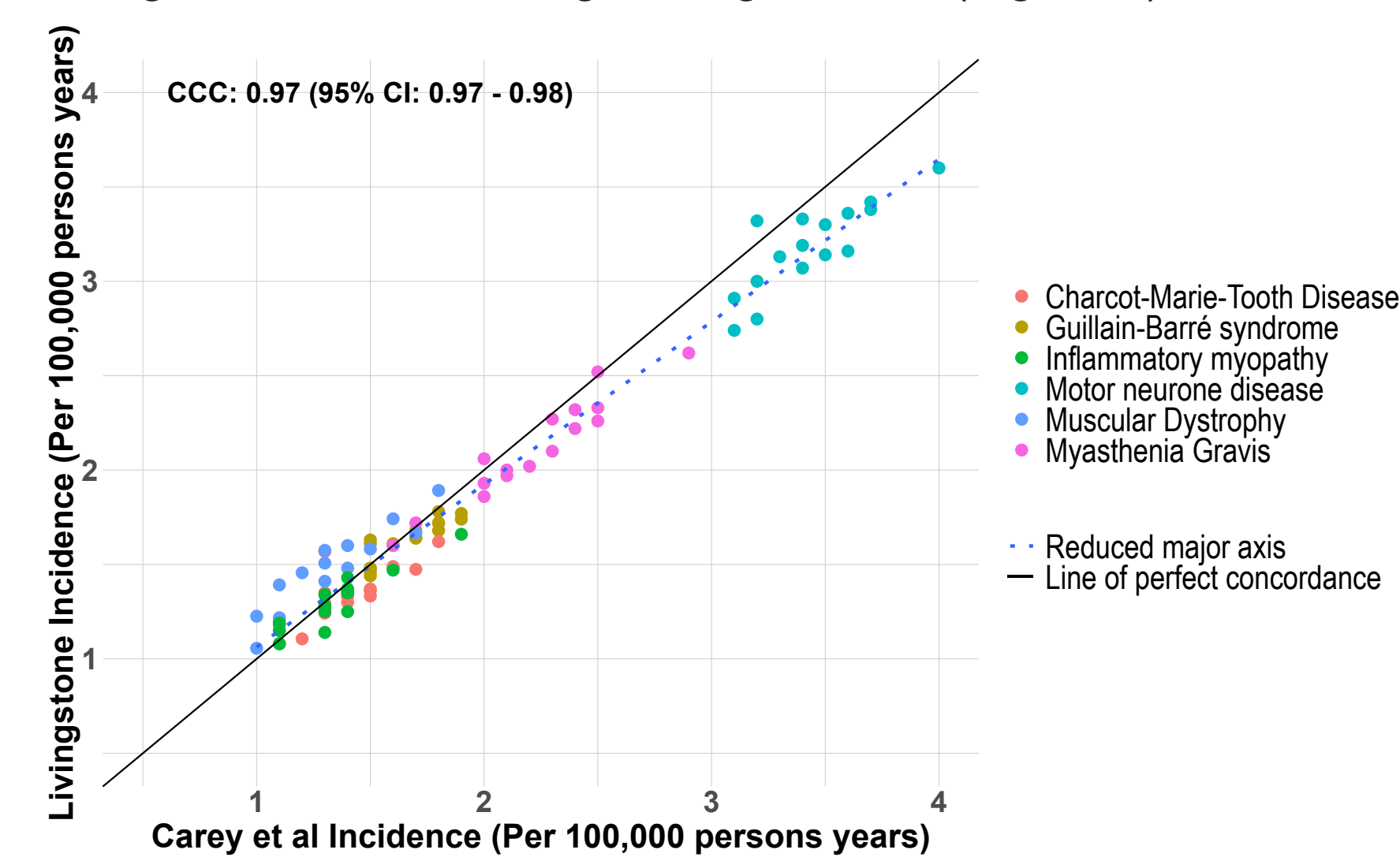


Figure 3: Comparison of incidence estimates between Livingstone and Carey et al.

### Condition-Specific Incidence Concordance

- The CCC of Guillain-Barré syndrome, inflammatory myopathy, and myasthenia gravis were 0.80 or above.
- The CCC of MND was 0.52 (0.25–0.72). This showed the lowest level of concordance with a poor strength of agreement (Table 3).
- Figure 4 shows the comparison between estimates by Livingstone and Carey et al split by condition.

Table 3: Incidence concordance correlation coefficient split by condition.

Condition	Concordance correlation coefficient (CCC)	95% Confidence Interval
Guillain-Barré syndrome	0.80	(0.58 - 0.91)
Charcot-Marie-Tooth disease	0.61	(0.27 - 0.82)
Inflammatory myopathy	0.86	(0.70 - 0.94)
Myasthenia gravis	0.89	(0.75 - 0.95)
Motor neurone disease	0.52	(0.25 - 0.72)
Muscular dystrophy	0.78	(0.56 - 0.89)

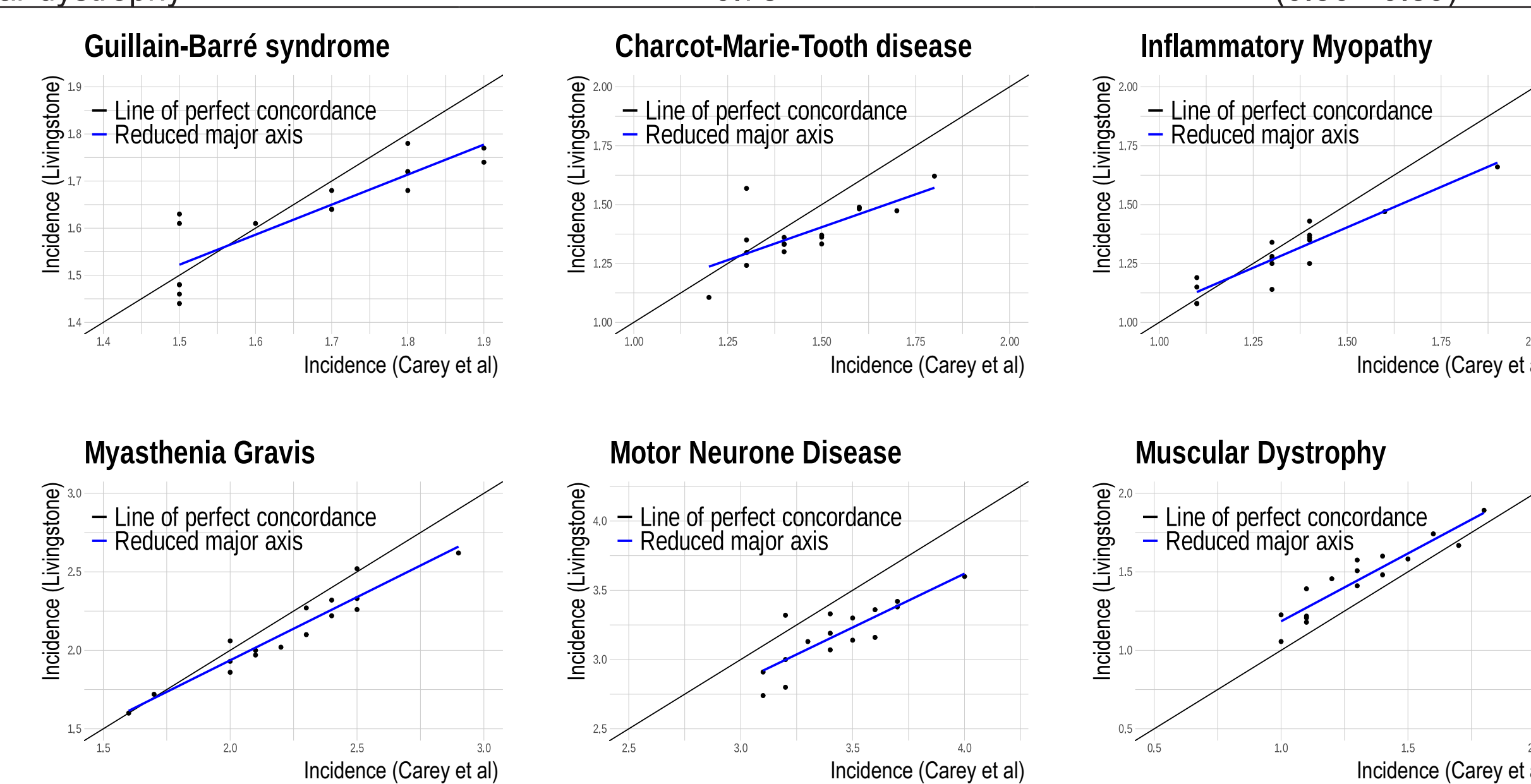


Figure 4: Comparison of incidence estimates between Livingstone and Carey et al split by condition.

## CONCLUSION

- For the six conditions considered together, there was excellent concordance between Livingstone and the published results for both incidence and prevalence.
- There were also high levels of concordance for the majority of estimates for the individual conditions by year.
- Due to the relative consistency of prevalence estimates over the study period for MDN and MD, the underlying bivariate distribution was heavy-tailed and thus Lin's CCC was less robust in these two conditions.
- This demonstrates that Livingstone is able to replicate estimates of prevalence and incidence derived from routine database analyses representing savings in time and costs. Livingstone may also ensure reproducibility and validity.

## REFERENCES

- Carey IM, Banchoff E, Nirmalanathan N, Harris T, DeWilde S, Chaudhry UAR, Cook DG. Prevalence and incidence of neuromuscular conditions in the UK between 2000 and 2019: A retrospective study using primary care data. PLoS One. 2021 Dec 31;16(12):e0261983. doi: 10.1371/journal.pone.0261983. PMID: 34972157; PMCID: PMC8719665.
- McBride GB. A proposal for strength-of-agreement criteria for Lin's concordance correlation coefficient. NIWA client report: HAM2005-062. 2005 May;45:307-10.