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# Regional and socioeconomic disparities in the diagnosis of primary electrical diseases in a universal healthcare system: a nationwide Danish study

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## Aims

Primary electrical diseases (PED) carry a significant risk of sudden cardiac death (SCD). Diagnosis, management, and access to care vary across regions even within universal healthcare systems. We examined nationwide geographic, socioeconomic, and treatment disparities in Denmark.

## Methods and results

We conducted a nationwide registry-based study of individuals diagnosed with PED (long QT syndrome, Brugada syndrome, catecholaminergic polymorphic ventricular tachycardia) between 2007 and 2024 in Denmark. Cases were compared with sex- and age-matched individuals in the background population. Outcomes included disease prevalence, proximity to specialized clinics, treatment patterns, comorbidities, and socioeconomic status. We identified 1132 individuals with PED. Overall prevalence was 19.0 per 100,000, with regional variation highest in North Denmark (26.8) and lowest in Central Denmark (12.9). Prevalence was higher in capital municipalities than in other municipality types. Cases lived closer to specialized inherited cardiac clinics than matched controls (50% shorter distance in the Capital Region; 18.9% shorter in Southern Denmark). Psychiatric comorbidities, notably anxiety and affective disorders, were more frequent in cases than controls (15% vs. 11%). Beta-blocker use and ICD implantation were markedly higher in cases with regional variation. Socioeconomic differences were modest, with immigrants underrepresented among diagnosed cases.

## Conclusion

Even within a universal healthcare system, geographic and systemic factors contribute to disparities in the diagnosis and management of PED. Differences in proximity to specialized clinics, regional referral practices, and treatment patterns may influence detection and care. Targeted strategies to improve awareness, referral pathways, and equitable access are needed to optimize diagnosis, management, and SCD prevention.

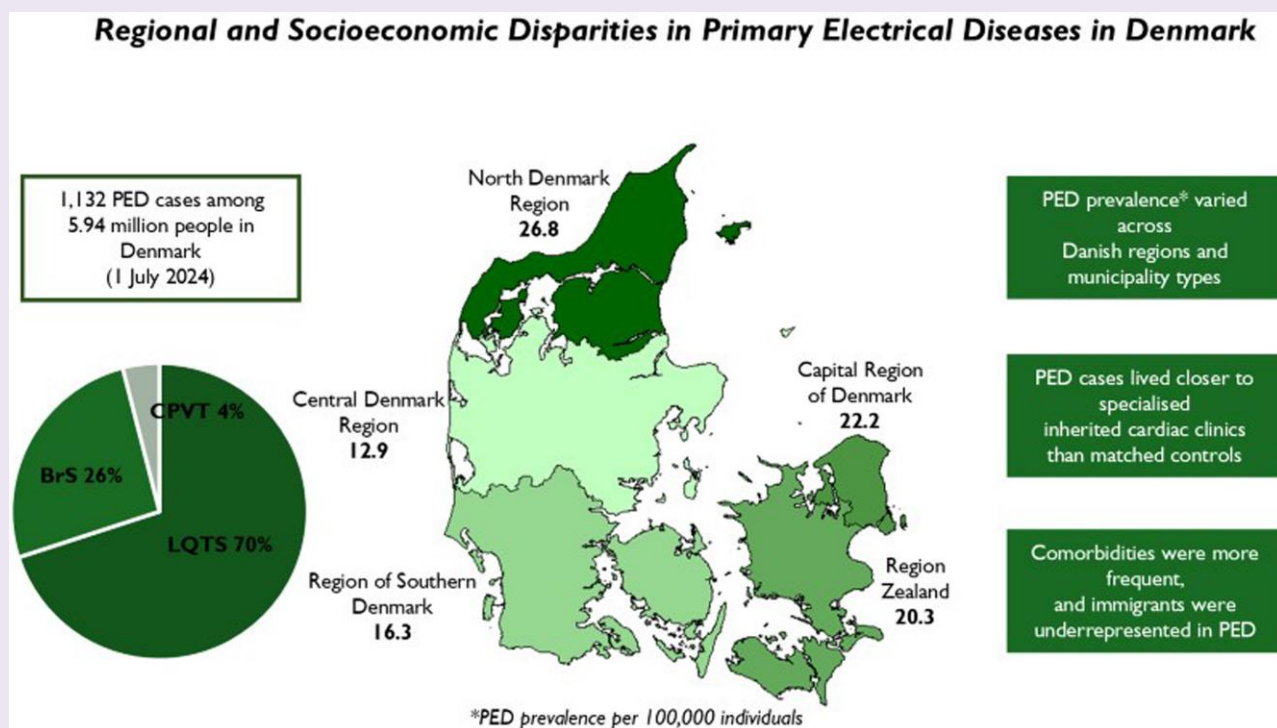
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## Graphical abstract



## Keywords

Primary electrical diseases • Healthcare disparities • Quality of care • SCD

## Key Learning Points

What is already known:

- Primary electrical diseases (PED), including LQTS, Brugada syndrome, and CPVT, are rare but carry a high risk of sudden cardiac death (SCD).
- Early identification and management, and family cascade screening, improve outcomes.
- Access to specialized care and regional/socioeconomic factors may influence diagnosis and treatment, but nationwide data are limited.

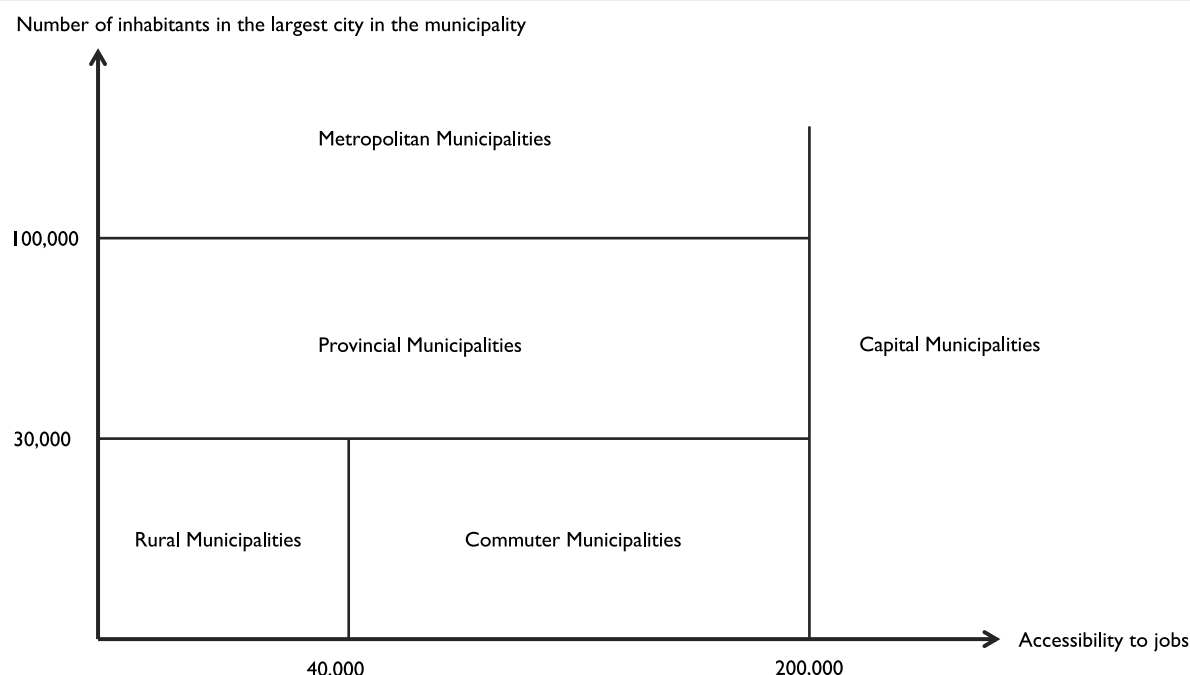
What this study adds:

- Provides nationwide overview of PED prevalence and regional variation in Denmark, highlighting differences across regions and municipality types.
- Demonstrates that patients with PED live closer to specialized inherited cardiac clinics and receive more intensive management than controls, but regional disparities in care persist.
- Shows that psychiatric comorbidities are more common in individuals with PED, and that socioeconomic disparities, may influence access to diagnosis and treatment.

## Background

Primary electrical diseases (PED), including long-QT syndrome (LQTS), Brugada syndrome (BrS), and catecholaminergic polymorphic ventricular tachycardia (CPVT) are associated with sudden cardiac death (SCD) as the first clinical manifestation.<sup>1</sup> Although rare, the public health impact is significant

due to the severity of clinical outcomes. Population prevalence estimates are approximately 1 in 2000 for LQTS, 1 in 5000 for BrS, and much lower for CPVT, varying between 1 in 15 000 to 1 in 50 000.<sup>2–6</sup> Early identification and management, including family cascade screening and timely interventions such as lifestyle advice, beta-blocker treatment or implantable cardioverter-defibrillators (ICDs), are critical for



**Figure 1** Criteria for classification of municipalities. Municipalities were categorized using Statistics Denmark's national model based on population size and job accessibility. Capital municipalities had job accessibility  $\geq 200\,000$ . Municipalities below this threshold were classified as metropolitan ( $\geq 100\,000$  inhabitants in the largest city), Provincial ( $\geq 30\,000$  inhabitants), or when  $< 30\,000$  inhabitants as commuter (job accessibility  $\geq 40\,000$ ) or rural ( $< 40\,000$ ).

improving survival. Recent nationwide data from Denmark show a substantial increase in diagnostic rates of inherited cardiac diseases and greater use of ICDs, coinciding with a nearly 50% decline in SCD incidence among young individuals over the past two decades, highlighting the importance of early identification.<sup>7</sup>

In Denmark, individuals with suspected inherited arrhythmias are referred to one of seven designated inherited heart outpatient clinics where comprehensive evaluation, including genetic testing, is performed.<sup>8</sup> When a PED is diagnosed, first degree relatives are invited for diagnostic evaluation. Following diagnosis, patients receive lifelong follow-up as recommended in the European Society of Cardiology guidelines.<sup>1</sup>

Despite this structured approach, systemic and procedural barriers may delay timely diagnosis. Under the General Data Protection Regulation (GDPR), clinics cannot directly contact relatives without patient consent, potentially limiting cascade screening efforts. Additionally, geographic proximity to specialized clinics, socioeconomic status (SES), and patterns of healthcare utilization can influence diagnostic rates and access to care.<sup>9</sup> Similar challenges have been observed internationally; in a study from the Netherlands, found that referrals for genetic diagnostics in LQTS varied by region, resulting in identification of a small number of mutation carriers over a 10-year period.<sup>10</sup>

In this nationwide study, we investigated regional variation in the prevalence of PED across Denmark, focusing on geographic and socioeconomic variation. We further explored differences in treatment patterns, including beta-blockers and ICD implantation, to identify potential barriers to equitable care and early diagnosis identification of at-risk individuals.

## Methods

### Study design and population

We conducted a nationwide registry-based study of individuals diagnosed with PED in Denmark between 1 January 2007 and 1 July 2024. The 2007 cut-off was chosen to ensure diagnostic accuracy, reflecting the period after national clinical guidelines were introduced by the Danish Society of Cardiology.<sup>11</sup> Patients were included at the time of their first recorded diagnosis of LQTS, BrS, or CPVT. Individuals with acquired LQTS were excluded, since majority of these cases are not monogenic inherited arrhythmias. Using the unique Danish personal civil registration number, we linked national health registries to identify eligible patients and matched each case to ten population controls who were alive, residing in Denmark, and free of a PED on the index date.

### Data sources

Patients were identified through the Danish National Patient Register, which records all hospital contacts and diagnoses using the International Classification of Diseases, 10th Revision (ICD-10) codes: DI472E for LQTS, DI472F for acquired long QT syndrome (aLQTS), DI472M for BrS, and DI472H for CPVT.<sup>12</sup> Demographic and residence information was obtained from the Danish Civil Registration System.<sup>13</sup> Prescription medication data were collected from the Danish National Prescription Register, which captures all dispensed prescriptions nationwide according to the Anatomical Therapeutic Chemical classification system.<sup>14</sup> Socioeconomic data were obtained from the Danish Income Statistics Register. Household income was indexed to account for household composition using the Organization for Economic Co-operation and Development's weighting scale.<sup>15</sup> Education level was classified according to the International Standard Classification of Education.<sup>16</sup> ICD implantation was identified using the Danish Pacemaker and ICD Register.<sup>17</sup>

**Table 1** Baseline characteristics of primary electrical disease cases vs. a sex and age matched control group

| Characteristic                      | Primary electrical disease Cases<br><i>n</i> = 1,132 <sup>a</sup> | Matched Control Group<br><i>n</i> = 11,320 <sup>a</sup> | <i>P</i> -value <sup>b</sup> |
|-------------------------------------|-------------------------------------------------------------------|---------------------------------------------------------|------------------------------|
| Male sex                            | 516 (46%)                                                         | 5160 (46%)                                              | >0.9                         |
| Age                                 | 46 (27, 60)                                                       | 46 (27, 60)                                             | >0.9                         |
| Primary electrical disease          |                                                                   |                                                         |                              |
| LQTS                                | 792 (70%)                                                         | —                                                       | —                            |
| BrS                                 | 296 (26%)                                                         | —                                                       | —                            |
| CPVT                                | 44 (4%)                                                           | —                                                       | —                            |
| Live alone                          | 287 (25%)                                                         | 2996 (26%)                                              | 0.4                          |
| Nationality                         |                                                                   |                                                         | <0.001                       |
| Danish origin                       | 1023 (90%)                                                        | 9624 (85%)                                              | —                            |
| Immigrant                           | 109 (9.6%)                                                        | 1696 (15%)                                              | —                            |
| ISCED level                         |                                                                   |                                                         | 0.6                          |
| High                                | 371 (36%)                                                         | 3706 (36%)                                              | —                            |
| Medium                              | 408 (40%)                                                         | 3938 (38%)                                              | —                            |
| Low                                 | 252 (24%)                                                         | 2629 (26%)                                              | —                            |
| Household income, DKK annually      | 293 789 (213,734, 392,770)                                        | 282 928 (202,732, 386,865)                              | 0.001                        |
| Source of income                    |                                                                   |                                                         | 0.06                         |
| Employed                            | 588 (52%)                                                         | 5918 (53%)                                              | —                            |
| Retired                             | 169 (15%)                                                         | 1648 (15%)                                              | —                            |
| Studying                            | 102 (9.1%)                                                        | 1088 (9.7%)                                             | —                            |
| Transfer income                     | 139 (12%)                                                         | 1105 (9.8%)                                             | —                            |
| Other                               | 129 (11%)                                                         | 1472 (13%)                                              | —                            |
| Years with disease                  | 8.0 (3.9, 11.4)                                                   | —                                                       | —                            |
| Distance to specialized clinic      | 20 (4, 45)                                                        | 25 (4, 54)                                              | <0.001                       |
| Comorbidity                         |                                                                   |                                                         |                              |
| Atrial fibrillation                 | 61 (5.4%)                                                         | 268 (2.4%)                                              | <0.001                       |
| Ischaemic heart disease             | 63 (5.6%)                                                         | 328 (2.9%)                                              | <0.001                       |
| Myocardial infarction               | 18 (1.6%)                                                         | 119 (1.1%)                                              | 0.1                          |
| Heart failure                       | 40 (3.5%)                                                         | 125 (1.1%)                                              | <0.001                       |
| Stroke                              | 29 (2.6%)                                                         | 211 (1.9%)                                              | 0.1                          |
| Cancer                              | 62 (5.5%)                                                         | 555 (4.9%)                                              | 0.4                          |
| Diabetes                            | 51 (4.5%)                                                         | 357 (3.2%)                                              | 0.02                         |
| Psychiatric disorders               | 172 (15%)                                                         | 1189 (11%)                                              | <0.001                       |
| Schizophrenia                       | 18 (1.6%)                                                         | 114 (1.0%)                                              | 0.07                         |
| Affective disorders                 | 50 (4.4%)                                                         | 322 (2.8%)                                              | 0.003                        |
| Anxiety                             | 98 (8.7%)                                                         | 549 (4.8%)                                              | <0.001                       |
| Treatment                           |                                                                   |                                                         |                              |
| Betablocker usage overall           | 569 (50%)                                                         | 733 (6.5%)                                              | <0.001                       |
| Non-selective beta-blockers (C07AA) | 501 (44%)                                                         | 615 (5.4%)                                              | <0.001                       |
| Selective beta-blockers (C07AB)     | 44 (3.9%)                                                         | 41 (0.4%)                                               | <0.001                       |
| Alpha- and beta-blockers (C07AG)    | 24 (2.1%)                                                         | 77 (0.7%)                                               | <0.001                       |
| ICD overall                         | 318 (28%)                                                         | 13 (0.1%)                                               | <0.001                       |
| LQTS                                | 173 (54.4% of ICDs)                                               |                                                         |                              |
| BrS                                 | 112 (35.2% of ICDs)                                               |                                                         |                              |
| CPVT                                | 36 (11.3% of ICDs)                                                |                                                         |                              |

DKK, Danish Krone; ICD, implantable cardioverter-defibrillator; ISCED, International Standard Classification of Education.

<sup>a</sup>*n* (%); Median (Q1, Q3)<sup>b</sup>Pearson's chi-squared test; Wilcoxon rank sum test

**Table 2** Baseline characteristics of primary electrical disease cases across regions

| Characteristic                 | Capital (n = 422) <sup>a</sup> | Central (n = 176) <sup>a</sup> | Northern (n = 159) <sup>a</sup> | Zealand (n = 173) <sup>a</sup> | Southern (n = 202) <sup>a</sup> | P-value |
|--------------------------------|--------------------------------|--------------------------------|---------------------------------|--------------------------------|---------------------------------|---------|
| Male sex                       | 202 (48%)                      | 70 (40%)                       | 71 (45%)                        | 79 (46%)                       | 94 (47%)                        | 0.5     |
| Age                            | 42 (26, 58)                    | 42 (26, 57)                    | 48 (28, 63)                     | 51 (32, 62)                    | 50 (29, 62)                     | 0.006   |
| Primary electrical disease     |                                |                                |                                 |                                |                                 | 0.002   |
| LQTS                           | 277 (66%)                      | 142 (81%)                      | 116 (73%)                       | 118 (68%)                      | 139 (69%)                       | —       |
| BrS                            | 129 (31%)                      | 27 (15%)                       | 35 (22%)                        | 48 (28%)                       | 57 (28%)                        | —       |
| CPVT                           | 16 (4%)                        | 7 (4%)                         | 8 (8%)                          | 7 (4%)                         | 6 (3%)                          | —       |
| Live alone                     | 101 (24%)                      | 48 (27%)                       | 38 (24%)                        | 45 (26%)                       | 55 (27%)                        | 0.8     |
| Nationality                    |                                |                                |                                 |                                |                                 | <0.001  |
| Danish origin                  | 343 (81%)                      | 173 (98%)                      | 152 (96%)                       | 164 (95%)                      | 191 (95%)                       |         |
| Immigrant                      | 79 (19%)                       | 3 (1.7%)                       | 7 (4.4%)                        | 9 (5.2%)                       | 11 (5.4%)                       |         |
| ISCED level                    |                                |                                |                                 |                                |                                 | <0.001  |
| High                           | 186 (50%)                      | 54 (34%)                       | 37 (25%)                        | 44 (27%)                       | 50 (27%)                        | —       |
| Medium                         | 110 (29%)                      | 70 (43%)                       | 64 (43%)                        | 75 (45%)                       | 89 (49%)                        | —       |
| Low                            | 79 (21%)                       | 37 (23%)                       | 47 (32%)                        | 46 (28%)                       | 43 (24%)                        | —       |
| Household income, DKK annually | 308 288 (207,052, 444,622)     | 274 484 (197,266, 356,975)     | 268 591 (214,315, 371,872)      | 307 282 (246,929, 403,728)     | 285 011 (209,023, 376,934)      | <0.001  |
| Source of income               |                                |                                |                                 |                                |                                 | 0.4     |
| Employed                       | 225 (54%)                      | 92 (52%)                       | 81 (51%)                        | 95 (55%)                       | 95 (47%)                        | —       |
| Retired                        | 49 (12%)                       | 25 (14%)                       | 28 (18%)                        | 28 (16%)                       | 39 (19%)                        | —       |
| Studying                       | 41 (9.8%)                      | 20 (11%)                       | 11 (6.9%)                       | 16 (9.2%)                      | 14 (6.9%)                       | —       |
| Transfer income                | 48 (12%)                       | 22(13%)                        | 19 (12%)                        | 22 (13%)                       | 28 (15%)                        | —       |
| Other                          | 54 (13%)                       | 17 (9.7%)                      | 20 (13%)                        | 12 (6.9%)                      | 26 (13%)                        | —       |
| Years with disease             | 6.7 (3.4, 11.3)                | 7.3 (3.7, 11.2)                | 10.3 (6.3, 13.6)                | 7.7 (4.8, 11.7)                | 8.5 (3.6, 11.0)                 | <0.001  |
| Distance to specialized clinic | 5 (4, 20)                      | 51 (36, 81)                    | 20 (2, 43)                      | 33 (20, 56)                    | 30 (3, 63)                      | <0.001  |
| Comorbidity                    |                                |                                |                                 |                                |                                 |         |
| Atrial fibrillation            | 17 (4.0%)                      | 4 (2.3%)                       | 8 (5.0%)                        | 18 (10%)                       | 14 (6.9%)                       | 0.006   |
| Ischaemic heart disease        | 22 (5.2%)                      | 13 (7.4%)                      | 6 (3.8%)                        | 12 (6.9%)                      | 10 (5.0%)                       | 0.6     |
| Myocardial infarction          | 4 (0.9%)                       | 4 (2.3%)                       | ≤ 4                             | 4 (2.3%)                       | ≤ 4                             | 0.5     |
| Heart failure                  | 10 (2.4%)                      | 5 (2.8%)                       | 4 (2.5%)                        | 9 (5.2%)                       | 12 (5.9%)                       | 0.12    |
| Stroke                         | 7 (1.7%)                       | ≤ 4                            | 4 (2.5%)                        | 12 (6.9%)                      | ≤ 4                             | 0.01    |
| Cancer                         | 18 (4.3%)                      | 8 (4.5%)                       | 10 (6.3%)                       | 9 (5.2%)                       | 17 (8.4%)                       | 0.3     |
| Diabetes                       | 18 (4.3%)                      | 6 (3.4%)                       | 7 (4.4%)                        | 10 (5.8%)                      | 10 (5.0%)                       | 0.9     |
| Psychiatric disorders          | 54 (13%)                       | 23 (13%)                       | 19 (12%)                        | 33 (19%)                       | 43 (21%)                        | 0.02    |
| Schizophrenia                  | 6 (1.4%)                       | 4 (2.3%)                       | ≤ 4                             | 4 (2.3%)                       | ≤ 4                             | 0.8     |
| Affective disorders            | 21 (5.0%)                      | 10 (5.7%)                      | 5 (3.1%)                        | 6 (3.5%)                       | 8 (4.0%)                        | 0.7     |

Continued

Table 2 Continued

| Characteristic    | Capital (n = 422 <sup>a</sup> ) | Central (n = 176 <sup>a</sup> ) | Northern (n = 159 <sup>a</sup> ) | Zealand (n = 173 <sup>a</sup> ) | Southern (n = 202 <sup>a</sup> ) | P-value |
|-------------------|---------------------------------|---------------------------------|----------------------------------|---------------------------------|----------------------------------|---------|
| Anxiety           | 31 (7.3%)                       | 9 (5.1%)                        | 13 (8.2%)                        | 25 (14%)                        | 20 (9.9%)                        | 0.02    |
| Treatment         |                                 |                                 |                                  |                                 |                                  |         |
| Betablocker usage | 185 (44%)                       | 95 (54%)                        | 89 (56%)                         | 92 (53%)                        | 108 (53%)                        | 0.02    |
| ICD               | 101 (24%)                       | 53 (30%)                        | 49 (31%)                         | 47 (27%)                        | 68 (34%)                         | 0.1     |

<sup>a</sup>n (%); Median (Q1, Q3)  
DKK, Danish Krone; ICD, implantable cardioverter-defibrillator; ISCED, International Standard Classification of Education.

All baseline characteristics, comorbidities, socioeconomic factors, medication use, and distance to specialized inherited cardiac clinics were defined at the index date.

Validation of diagnosis

The validity of LQTS and BrS diagnoses has previously been evaluated at Rigshospitalet, Copenhagen University Hospital, with manual review of medical records confirming positive predictive values of 97.6% for LQTS and 95.8% for BrS. These results support the reliability of registry-based identification of patients with PED in Denmark.<sup>18,19</sup> CPVT diagnoses have not undergone local validation but are based on national registry coding.

Geographical distribution

Prevalence of diagnoses were assessed across the five administrative regions of Denmark (North Denmark, Central Denmark, Southern Denmark, Zealand, Capital Region) and across all 98 municipalities. Municipalities were grouped based on population size and job accessibility, according to Statistics Denmark's classification (capital, metropolitan, provincial, commuter, rural), with job accessibility defined as the number of reachable workplaces by car within a given time frame from each municipality. Capital municipalities had job accessibility ≥200 000. Municipalities below this threshold were classified as metropolitan (≥100 000 inhabitants in the largest city), Provincial (≥30 000 inhabitants), or when <30 000 inhabitants as commuter (job accessibility ≥40 000) or rural (<40 000) (Figure 1).<sup>20</sup> To assess proximity to a specialized inherited heart clinic, the shortest driving route from each municipality's town hall to the nearest specialized inherited cardiac disease clinic was calculated using Google Maps.

Outcomes

The primary outcome was the prevalence of diagnosed PED in the population and stratified by region. Secondary outcomes included proportions of patients with ICDs and beta-blocker prescription, both overall and by region.

Statistical methods

Baseline characteristics were summarized using proportions for categorical variables and medians with interquartile ranges for continuous variables. Prevalences were calculated as the number of diagnosed cases divided by the total population at risk, with exact 95% confidence intervals computed by the Poisson method. Each case was matched 1:10 to population controls on age, sex, and region of residence at the index date and not yet diagnosed with a PED, ensuring controls were at risk at the time of case diagnosis. Regional variation in ICD implantation and beta-blocker medication use was assessed using  $\chi^2$  tests or logistic regression where appropriate.

Results

Baseline characteristics, comorbidities, medication use, and socioeconomic factors

Between 1 January 2007 and 1 July 2024, we identified 1132 individuals with PED (70% LQTS, 26% BrS, 4% CPVT). Individuals with PED had a higher prevalence of cardiovascular comorbidities, including atrial fibrillation, ischaemic heart disease, and heart failure, as well as diabetes, compared with matched controls. Psychiatric disorders were also more common, driven primarily by anxiety and affective disorders. Cases had higher rates of beta-blocker use and ICD implantation than controls. Overall, 50% received beta-blockers and the majority received selective beta-blockers.

ICD implantation was reported in 28% cases, the majority had LQTS. Socioeconomic differences were generally modest. Cases



**Table 3** Prevalence of primary electrical diseases across Denmark

| Classification              | Cases | Prevalence* | 95% CI    | Prevalence Ratio | 95% CI    | P value |
|-----------------------------|-------|-------------|-----------|------------------|-----------|---------|
| Total                       | 1132  | 19.0        | 18.0–20.2 |                  |           |         |
| Region                      |       |             |           |                  |           |         |
| Capital Region of Denmark   | 422   | 22.2        | 20.1–24.4 | Reference        |           |         |
| Region Zealand              | 173   | 20.3        | 17.4–23.6 | 0.915            | 0.77–1.09 | 0.325   |
| Region of Southern Denmark  | 202   | 16.3        | 14.1–18.7 | 0.735            | 0.62–0.87 | <0.001  |
| Central Denmark Region      | 176   | 12.9        | 11.1–15.0 | 0.582            | 0.49–0.69 | <0.001  |
| North Denmark Region        | 159   | 26.8        | 22.8–31.3 | 1.21             | 1–1.44    | 0.0449  |
| Municipality groups         |       |             |           |                  |           |         |
| Capital municipalities      | 377   | 22.8        | 20.5–25.2 | Reference        |           |         |
| Metropolitan municipalities | 128   | 16.2        | 13.5–19.2 | 0.71             | 0.60–0.87 | <0.001  |
| Commuter municipalities     | 169   | 17.6        | 15.1–20.5 | 0.76             | 0.65–0.93 | 0.006   |
| Provincial municipalities   | 240   | 17.6        | 15.4–20.0 | 0.77             | 0.66–0.91 | 0.002   |
| Rural municipalities        | 218   | 18.6        | 16.2–21.2 | 0.82             | 0.69–0.96 | 0.02    |

\*Per 100,000 individuals.

were slightly more likely to be of Danish origin and had a marginally higher median household income, while employment status, educational level, and living-alone patterns were broadly similar between groups (Table 1).

Comorbidities, medication use, and socioeconomic factors were broadly consistent across regions, with only minor variation (Table 2; full data in Supplementary material online, Table S1).

**Regional variation and geographic access**

Diagnosed prevalence of PED varied across Denmark (Table 3). Overall prevalence was 19.0 per 100 000. North Denmark had the highest prevalence (26.8), with lower prevalence in the Capital, Southern, Central, and Zealand regions (Figure 2). Prevalence also varied across municipality groups, with the highest prevalence in capital municipalities (22.8) and lower prevalence in metropolitan, commuter, provincial, and rural municipalities (Figure 3).

Cases lived closer to specialized inherited cardiac clinics than matched controls. When distances were evaluated relative to matched controls, cases residing in the Capital Region lived 50% closer to a specialized clinic than controls, compared with an 18.9% shorter distance in Southern Denmark.

The relative distribution of LQTS, Brugada syndrome, and CPVT across regions is shown in Table 2.

**Discussion**

This nationwide study highlights regional variation in the prevalence of inherited PED in Denmark and identifies differences in comorbidity burden, socioeconomic factors, and access to specialized care compared with matched population controls. By focusing exclusively on PED and excluding acquired LQTS, we provide a clearer picture of true inherited disease patterns and associated healthcare disparities.

**Prevalence and healthcare system challenges**

Despite universal healthcare and comprehensive registries, the prevalence of PED in Denmark remains lower than expected

from international estimates.<sup>3–5</sup> Estimating the prevalence is challenging, as differences between regions may reflect both genuine variation in disease occurrence and factors such as specialist access, referral pathways, and clinician awareness. Denmark’s centralized system facilitates case identification, regional variation in access, local clinical practices, and regulatory limitations on cascade screening under GDPR may still influence patterns of diagnosis and treatment. These challenges reflect broader issues in rare disease care, where prolonged diagnostic journeys, fragmented care pathways, and limited awareness among primary care providers contribute to diagnostic gaps and unmet patient needs.<sup>21,22</sup> Improving early diagnosis and management requires strengthening integrated healthcare systems across healthcare sectors, with collaboration through centres of expertise, and enhancing education in both specialist and primary care settings.<sup>23</sup> Addressing these barriers is essential to improve identification and care of patients with PED.

These findings provide context for the subsequent exploration of patient demographics, regional differences, and socioeconomic disparities in Denmark.

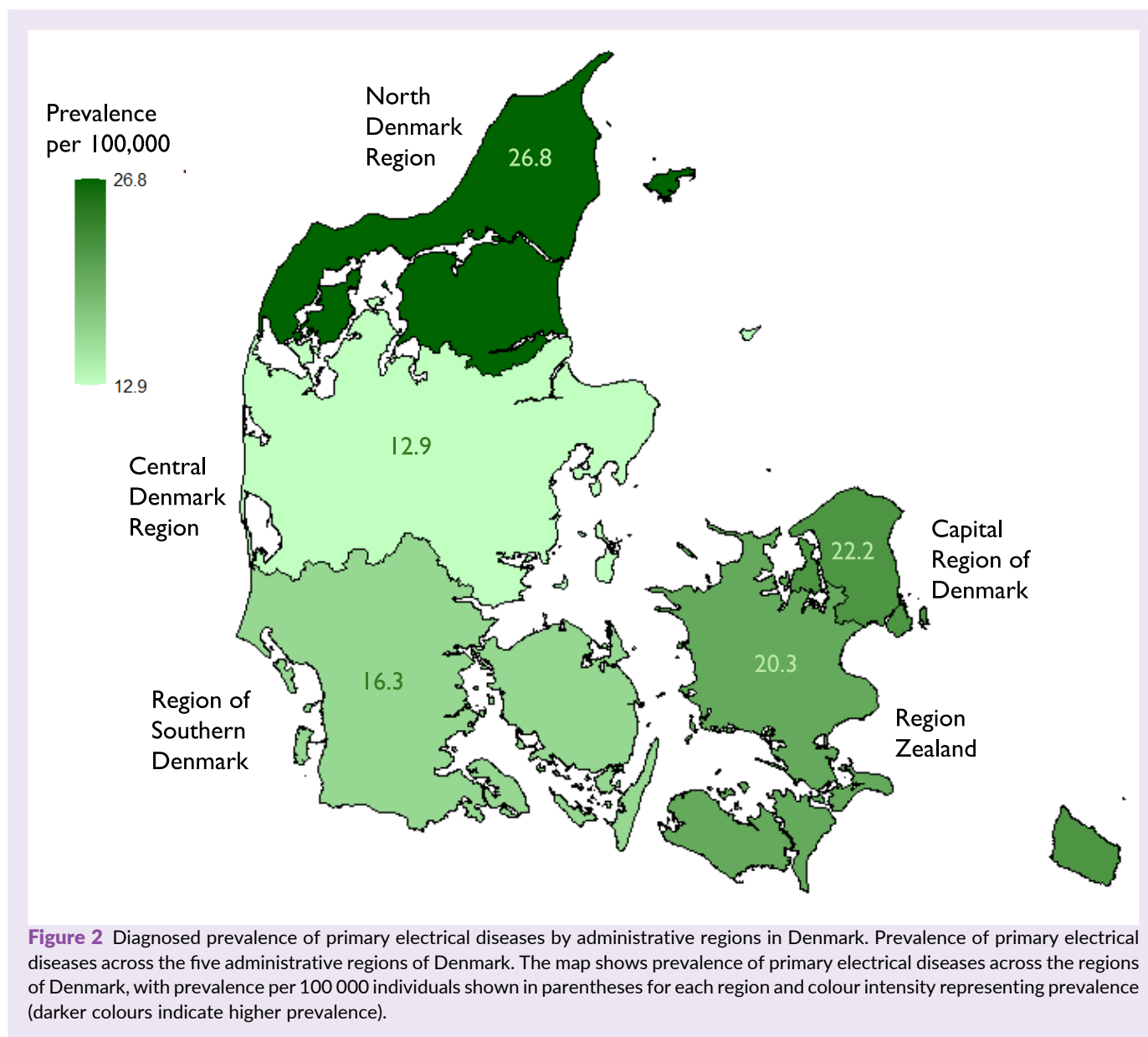
**Demographics and comorbidities**

Individuals with PED had higher rates of psychiatric comorbidities compared with matched controls, driven primarily by anxiety and affective disorders. This may reflect disease-related stress, frequent clinical monitoring, and treatment effects, such as beta-blocker-associated anxiety or insomnia, consistent with prior studies.<sup>18,24–26</sup> Elevated anxiety among relatives of affected individuals has also been reported, linked to fear of SCD and the psychological impact of living with a potentially life-threatening condition.<sup>27–29</sup> These findings highlight a persistent susceptibility to psychiatric disorders in individuals with PED. Further investigation is needed to explore the mechanisms and interactions between PED and psychiatric comorbidities.

**Regional variation and geographic access**

Significant regional variation was observed, with the highest prevalence in region North Denmark and lowest in Central





**Figure 2** Diagnosed prevalence of primary electrical diseases by administrative regions in Denmark. Prevalence of primary electrical diseases across the five administrative regions of Denmark. The map shows prevalence of primary electrical diseases across the regions of Denmark, with prevalence per 100 000 individuals shown in parentheses for each region and colour intensity representing prevalence (darker colours indicate higher prevalence).

Denmark region. Prevalence was consistently higher in capital municipalities than other municipality types. Patients with PED lived closer to specialized inherited cardiac clinics than matched controls, with the largest relative reduction in distance observed in the Capital Region and a smaller reduction in Southern Denmark, with no relative distance advantage was seen in Central Denmark, suggesting that referral pathways, local clinical practices, or diagnostic awareness may contribute to underdiagnosis.

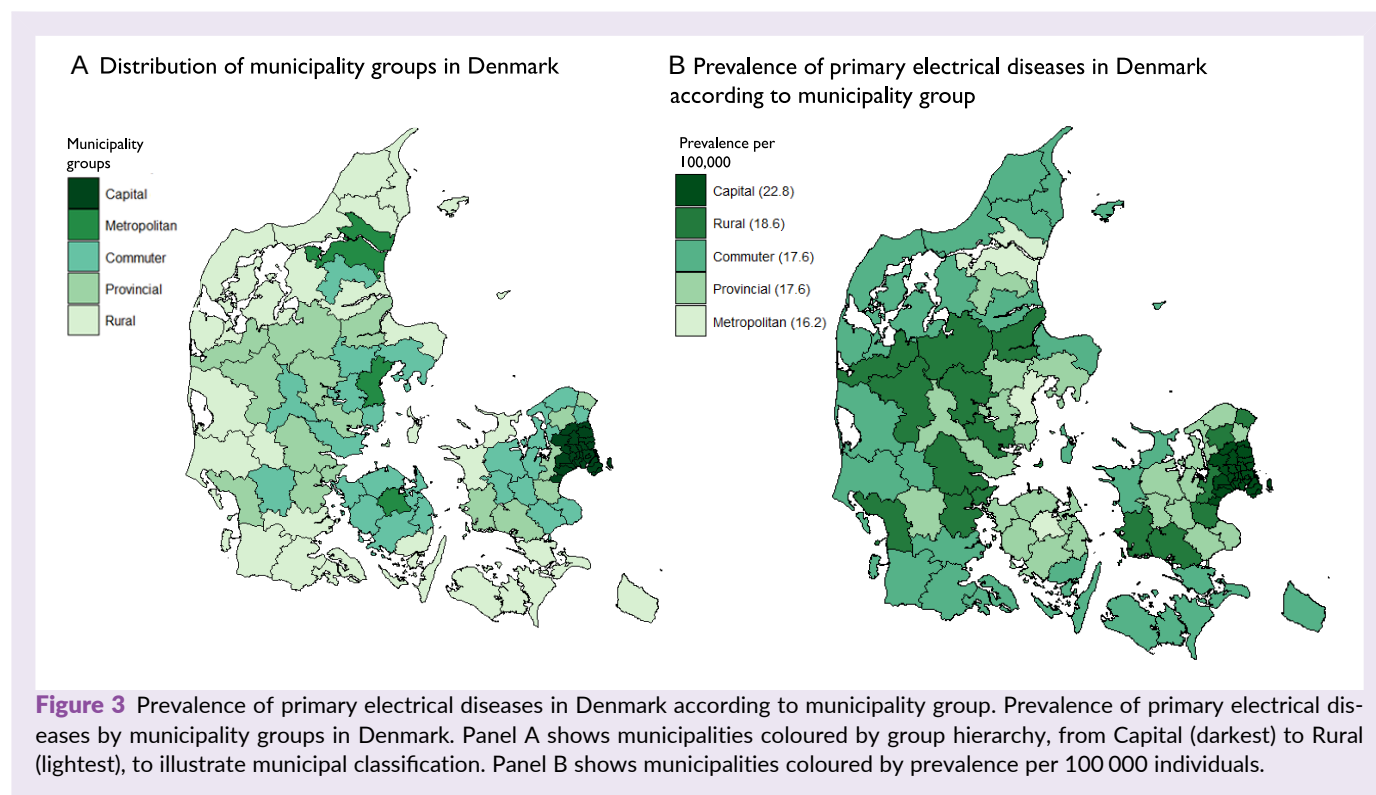
Treatment patterns were largely comparable across regions. Although no statistically significant regional differences were observed, a consistent trend towards lower use of both therapies was observed in the Capital region. These patterns may reflect regional variation in care pathways, access to specialized PED services, or differences in treatment thresholds, as reported previously.<sup>30–33</sup>

While Denmark's centralized healthcare system facilitates evaluation in nationally designated clinics, with lifelong follow-

up, observed differences suggest that systemic barriers, including geographic access, referral practices, and socioeconomic factors, may still influence diagnosis and management. Reducing these disparities will require not only optimizing geographic access but also enhancing clinical awareness, standardizing referral practices, and promoting early detection strategies to prevent SCD.

### Socioeconomic differences across regions

Patients with PED showed modest socioeconomic differences compared with matched controls. Immigrants were consistently underrepresented among diagnosed patients, suggestive of broader barriers related to healthcare access, health literacy, cultural factors and navigating the healthcare system.<sup>34–36</sup> These observations suggests that socioeconomic disparities exist beyond demographic differences. Structural factors within the healthcare system, including potential physician bias and



referral patterns, may further influence referral prevalences. Addressing these disparities will require targeted strategies to improve awareness, early diagnosis, and equitable access to specialized care.

## Limitations

This study benefits from comprehensive nationwide registry data, providing near-complete coverage and minimizing selection bias. Nevertheless, the retrospective, cross-sectional design precludes causal inference and cannot determinate the temporal sequence between PED and psychiatric comorbidities. While diagnostic coding for arrhythmias has been validated at our centre, regional variation in coding practices may result in underreporting or misclassification, and our data capture the date of diagnosis and hospital affiliation but cannot confirm whether all patients were managed exclusively in specialized inherited cardiac clinics, which may affect observed prevalence. Socioeconomic variables were captured at a single time point, potentially overlooking changes over time. Detailed clinical data, including symptom onset, diagnostic triggers, and family history, were unavailable, limiting the assessment of disease severity and treatment rationale. The absence of genetic data further restricts incorporation of guideline-based diagnostic criteria.

## Conclusions

In Denmark's universal healthcare system, diagnosis and treatment of PED vary regionally and are influenced by systemic and socioeconomic factors. Geographic proximity to specialized clinics, regional referral practices, and healthcare infrastructure may contribute to these disparities. Targeted strategies to

improve access, awareness, and referral pathways are needed to close these gaps and improve outcomes.

## Supplementary material

Supplementary material is available at *European Heart Journal—Quality of Care and Clinical Outcomes* online.

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## Data availability

All data relevant to the study are included in the article or uploaded as supplementary information. According to the Danish law, personal data on Danish citizens must not be exported.

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