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**EpilepsyPOWER: results from a three-year project  
to favour workplace inclusion of People with  
Epilepsy**

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## **Abstract**

### *Background*

Epilepsy is a chronic disorder affecting all aspects of individual life. The majority of people with epilepsy (PwE) are well controlled with antiseizure medication. However, epilepsy is more than seizures and there is a significant body of research that has documented the comorbidities of the epilepsy including issues such as social integration. Unemployment and underemployment for example are markedly more common in PwE compared to the general population. The “EpilepsyPOWER” is a European project, involving five countries (Italy, Bulgaria, France, Ireland, Germany), aimed to improve PwE workplace inclusion. Central to the project was the development of a review depicting the employment situation for PwE. The project also involved the creation of surveys, learning modules and an epilepsy-friendly label potential users.

### *Methods*

A systematic review on epilepsy and employment as part of EpilepsyPOWER Erasmus+ project (2021-1-IT02-KA220-ADU-000028349) was conducted. The search string employed was “Epilepsy AND Employment OR Job OR Work”.

Using the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA 2020) guidelines, 7272 articles were screened, and 55 articles were selected from 1958 to 2023. Data was extrapolated on employment rate and status, also considering people with specific epileptic syndromes. Finally, factors contributing to employment and unemployment were selected.

Two anonymous surveys were developed asking for PwE employment conditions, stigma and disclosure, and Higher Education Institutions (HEI) general knowledge and attitudes about epilepsy.

### *Results*

The review identified unemployment rates ranging from similar to twice to three times the rates of the general population, depending on the countries and years examined. When analysing factors contributing to employment conditions, most papers highlighted the importance of seizure control and employers’ attitudes.

There were 567 responses from PwE and 291 from HEI. Reported unemployment rates were: 7,9% in Italy, 6,7% Ireland, 8,5% France, 15% Germany, 9% Bulgaria; people fully employed: 42,9% in Italy, 53% Ireland, 31,7% France, 40% Germany, 47,9% Bulgaria. As for disclosure, in Italy 19% of PwE did not disclose their condition, whereas in Bulgaria 48,5% did not. As regards HEI, they correctly defined epilepsy as a neurological disorder, treatable in most cases. They know the general concept of epilepsy, but they do not know how to give medical aid to a person experiencing a seizure.

### *Conclusion*

Developing specific legislation and programs to include PwE in the workplace could help support social integration. Further, seizure control seems to be the most relevant factor influencing the possibility of getting and maintaining a good job, demonstrating the importance of providing continuous follow-up and the best medical care to all PwE. Exploring PwE work conditions and HEI perspectives could help to spread a good culture of inclusion and fight marginalization of PwE in workplaces, allowing them to get the right job positions and better quality of life.

## **Introduction**

Epilepsy is a common neurological disorder, characterized by recurrent unprovoked seizures, their causes and complications. It is a common clinical condition, affecting all aspects of individual life, including social integration[1]. Unpredictable seizures represent only a small piece of the complex and heterogeneous picture of this disorder. Epilepsy affects self-efficacy, psychological health and emotional adjustment, contributing to higher underemployment [2], [3], [4]. PwE deal every day with stigma and prejudiced attitudes. Adding to burden, drugs' side effects, comorbidities including depression and cognitive deficits, driving limitations negatively impact on educational attainment and employment [5], [6], [7].

False beliefs, misconceptions, and employers' concerns contribute to unemployment in PwE [8], [9], [10]. Thus, the employment situation for PwE can be described as a combination of internal (seizures, cognitive deficits, etc.) and external factors (stigma, employers' attitudes, etc.).

Employment is one of the main determinants of economic independence, self-worth, and individual identity. Being unemployed prompts a lack of independence, reduced self-esteem, increased feelings of stigma, and, consequently, lower quality of life [11], [12].

Despite good seizure control, unemployment is often observed in PwE [7]. The lack of knowledge, specific legislation, and inclusion programs hampers employment integration. Four key pieces of legislation (exceptions) worldwide must be highlighted:

- 1) the Americans with Disabilities Act (ADA) in the USA,
- 2) Health and Safety at Work Act (1974), the
- 3) Commonwealth Disability Discrimination Act (1992),
- 4) Equality Act (2010) in Europe, which covers epilepsy among general disability.

When hiring PwE, employers' misconceptions often include fear of higher absenteeism and accidents. Conversely, it has been shown that the risk of seizure-related accidents is comparable to that of injury not related to seizures [13], [14], [15]. Some studies found a higher risk of accidents among PwE, but these were not related

to seizures. Even though absenteeism and accidents are not higher in employees with epilepsy, PwE salaries appear to be lower than those of their colleagues [16].

While many authors attempted to describe the employment situation worldwide [2], [6], [17], estimating the real unemployment rate is still challenging. Epilepsy can be a “hidden condition”: PwE can conceal their disorder from employers, because of fear or stigma. This scenario can be interpreted as a break of trust [18]; thus, another key issue for employment among PwE is disclosure.

Aiming to obtain the maximum grade of scientific evidence from the available specific literature, we conducted a systematic review on the employment rate of PwE and factors influencing their employment and unemployment in Europe.

We focused on European literature since this review is a key activity of the EpilepsyPOWER project (2021-1-IT02-KA220-ADU-000028349), financed by the European Commission and Erasmus+, involving five European countries (Italy, Ireland, Bulgaria, France, Germany). The objectives of the EpilepsyPOWER project aimed to improve the inclusion of PwE in the job market, increase the number of people engaged in relevant corporate social responsibility epilepsy-friendly initiatives, spread culture and practice for the implementation of inclusion systems for PwE, support universities, companies, and small enterprises in inclusion improvement.

As part of the project, surveys were created to explore work conditions among PwE and evaluate knowledge of epilepsy among higher education institutions (HEI), describing results from a multicentric study.

Finally, aiming to fight stigma and improve information about epilepsy, two learning modules were developed to inform HEI and PwE, making their choices more aware. As a result, after studying these modules and taking a quiz created by expert neurologists, companies could apply to get the epilepsy friendly label certification, and, so, prove their inclusivity.

## **Review Methods**

### **Research strategy**

Articles were sought about epilepsy and employment on PubMed, Google Scholar, and Embase.

The search string was “Epilepsy AND Employment OR Job OR Work”. We used the RAYYAN review system, an online tool allowing for flawless collaborative systematic review [19].

Using the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA 2020) guidelines, a systematic review was performed on epilepsy and employment [20]

Fifty-five articles were selected among 7272 articles identified from 1958 to September 2023 (Figure 1).

We then grouped those articles between papers reporting employment status and papers only describing factors contributing to employment/unemployment. We also analysed specific cases: surgical patients and people with specific syndromes (e.g., Juvenile myoclonic epilepsy, childhood onset epilepsy, absence epilepsy).

### **Inclusion and exclusion criteria**

We have only included articles written in English and published in journals with good impact factors (IF) regarding employment conditions in different European countries, as a specific deliverable of the European Project EpilepsyPOWER (project 2021-1-IT02-KA220-ADU-000028349). We considered articles regarding people living in the UK, since it was part of the geographic area of the European Union (EU) and politically included in the EU until 2023. We excluded articles with wrong types of publication (e.g., letters to editors) or wrong population (e.g., people with disabilities and not suffering from epilepsy).

## Study selection

We screened papers using the artificial intelligence automatic Rayyan review system[19]. Abstract were selected by two investigators (GL) and Principal investigator (FN), basing on titles and abstracts. Two researchers independently reviewed selected articles and results. GA supervised the quality of selected papers and adherence to the proposed aim, trying to minimize selection bias risks.

We selected all papers containing the word “employment” and/or “employed” in the title or in the abstract, dividing them into manuscripts reporting rates of employment, articles reporting specific situations (including surgical outcomes) and disclosure issue. No articles were sought for retrieval after our selection.

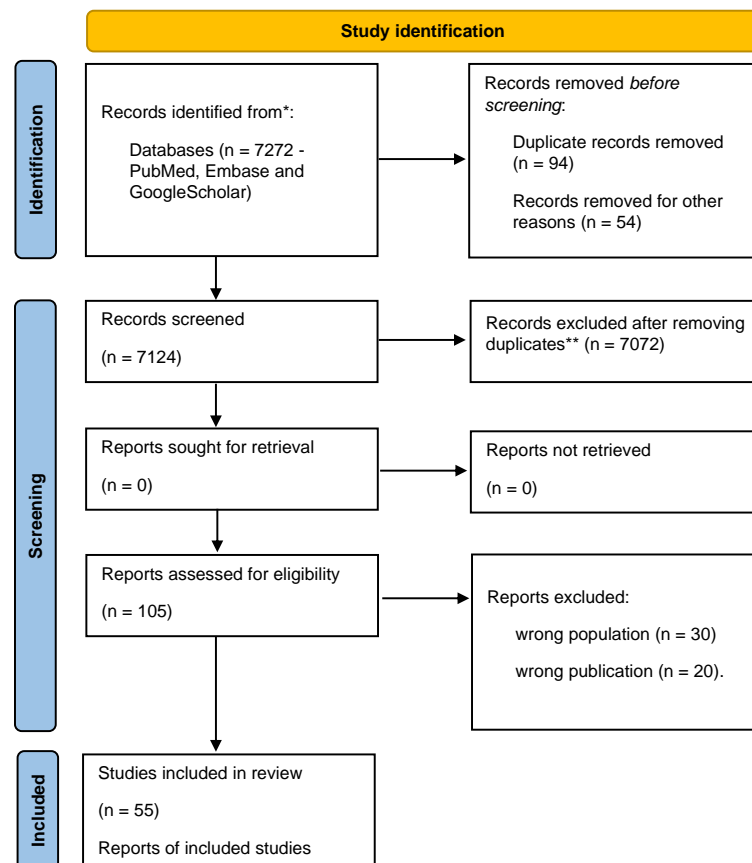


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses method

## **Employment status**

Selected manuscripts considered different sample dimensions, and they often did not report the specific rate of employment/unemployment.

Only a few articles (8) specified rates of retired PwE, the others included them into unemployed people, likewise for housewives and people receiving disability pension. No article specifically mentioned self-employment and only 3 papers mentioned part-time job. Therefore, despite the limitations, this category was considered among employed PwE.

Due to some limitations, the evaluation of the real rate of unemployment was not completely clear. Thus, we decided to list articles reporting same/different rate of employment/unemployment compared to the general population to find a trend in recent years. We specified the type of study, rates of employment/unemployment reported, and comparison with the general population.

## **Results**

Among manuscripts selected:

- 41 manuscripts reported employment status: 9 manuscripts reporting similar rates of employment/unemployment compared to the general population; 4 manuscripts reporting different rates of employment/unemployment compared to the general population (Tables 1 and 2).
- 8 manuscripts focused on surgical outcomes;
- 45 manuscripts reported factors contributing to employment/unemployment;
- 4 manuscripts regarded specific subtypes of epilepsy: childhood onset epilepsy, absence epilepsy, juvenile myoclonic epilepsy, and medial temporal lobe epilepsy;
- 6 manuscripts mentioned disclosure issues.

Most of the articles came from the UK (12), other articles examined the situation of Netherlands (6), Germany (5), Sweden (4), Estonia (3), Spain (3) Ireland (2), Denmark (2), Poland (2) and Finland (2).

| TITLE                                                                                                                   | AUTHOR      | YEAR | COUNTRY     | TYPE of Study                                     | Employment status                                                                                                                                                                                                                                                      | Population (N)                           | Comparison with general population |
|-------------------------------------------------------------------------------------------------------------------------|-------------|------|-------------|---------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------|------------------------------------|
| <b>SIMILAR RATES</b>                                                                                                    |             |      |             |                                                   |                                                                                                                                                                                                                                                                        |                                          |                                    |
| Social class, epileptic activity, and disadvantage at work                                                              | Scambler    | 1980 | UK          | survey                                            | 42/73 working age employed in full work:<br>31/42 men (74% vs 81% in general population);<br>6/19 married women (32% vs 48% in general population);<br>5/12 unmarried women (42% vs 42% in general population)                                                         | 94 PwE (73 respondents)                  | similar rate                       |
| Epilepsy and the quality of everyday life. Findings from a study of people with well-controlled epilepsy                | Jacoby      | 1992 | UK          | survey                                            | 79% of men and 63% of women under 60 employed.                                                                                                                                                                                                                         | 549 PwE                                  | similar rate                       |
| Correlates of employment history and employability in a British epilepsy sample                                         | Collings    | 1994 | UK          | survey                                            | 58% employed;<br>12% unemployed (vs 9% in general population);<br>18% students/housewife other                                                                                                                                                                         | 1709 PwE                                 | Similar rate                       |
| Impact of epilepsy on employment status: Findings from a UK study of people with well-controlled epilepsy               | Jacoby      | 1995 | UK          | prospective randomised controlled trial           | 71% employed;<br>26% unemployed because of other reasons;<br>3% unemployed because of seizures.                                                                                                                                                                        | 607 PwE                                  | similar rate                       |
| Felt stigma and impact of epilepsy on employment status among Estonian people: exploratory study                        | Rätsepp     | 2000 | Estonia     | survey                                            | full-time 38.9%;<br>part-time 24.0%;<br>unemployed 11%;<br>retired 10%;<br>receiving disablement pension 15.6%                                                                                                                                                         | 90 PwE                                   | similar rate                       |
| Epilepsy in Estonia: A Quality-of-Life Study                                                                            | Herodes     | 2001 | Estonia     | survey                                            | 33% full-time;<br>31.9% underemployed;<br>11%, unemployed (vs 9.5% in general population);<br>24.1% retired/disablement pension                                                                                                                                        | 203 PwE                                  | similar rate                       |
| Health perception and socioeconomic status following childhood-onset epilepsy: The Dutch study of epilepsy in childhood | Geerts      | 2011 | Netherlands | prospective cohort study                          | A total of 139 subjects (33.7%) had a job.<br>Employment rates (idiopathic 91.5%, symptomatic 91.3%, cryptogenic 97.1%, in remission 93.2%, active epilepsy 91.2%, Dutch age peers 92.0%).                                                                             | 413 people with childhood onset epilepsy | similar rate                       |
| Socio-occupational and employment profile of patients with epilepsy                                                     | Marinas     | 2011 | Spain       | cross-sectional multicenter epidemiological study | Employed 504 (58%) compared to 59.35% in first trimester of 2008 reported by Spanish National Statistics Institute<br>Unemployed 95 (10.9%)<br>Student 49 (5.6%)<br>Occupational incapacitation 109 (12.5%)<br>Housewife 107 (12.3%)<br>Employed and studying 5 (0.6%) | 872 adult PwE                            | similar rate                       |
| Long-term employment outcomes after epilepsy surgery in childhood                                                       | Reinholdson | 2019 | Sweden      | population based study                            | At the 10-, 15-, and 20-year follow-ups, 17/25 (68%); 22/29 (76%); 8/13 (62%) of the seizure-free patients aged $\geq 25$ years worked full-time. In the general population, the corresponding weighted figures were 66%, 66%, and 68%.                                | 203 surgical patients                    | similar rate                       |

**Table 1 Papers reporting similar rates of employment/unemployment.**

| TITLE                                                                                                        | AUTHOR              | YEAR | COUNTRY | TYPE of Study      | Employment status                                                                                                                                                                                                                                                                                                  | Population (N)                                                                                                        | Comparison with general population |
|--------------------------------------------------------------------------------------------------------------|---------------------|------|---------|--------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------|------------------------------------|
| <b>DIFFERENT RATES</b>                                                                                       |                     |      |         |                    |                                                                                                                                                                                                                                                                                                                    |                                                                                                                       |                                    |
| Epilepsy and employment, marital, education and social status                                                | Callaghan           | 1992 | Ireland | survey             | 34% of males and 28% of females unemployed (compared to 13% of males in general population); 53% of males and 24% of females gainfully employed; 1% of males and 41% of females house duties; 8% of males and 7% of females in sheltered employment; 4% of males and <1% of females retired.                       | 343 PwE                                                                                                               | Higher rate of unemployment        |
| Epilepsy-related employment prevalence and retirement incidence in German working population: 1994-2009      | Korchounov          | 2012 | Germany | longitudinal study | Mean employment rate of PwE was lower than that of the general population (68.5% vs 90.1%, P<0.001).                                                                                                                                                                                                               | n/a                                                                                                                   | Lower rate of employment           |
| Employment in people with epilepsy from the perspectives of patients, neurologist and the general population | Majkowska-Zwolinska | 2012 | Poland  | survey             | 486 (49%) were professionally active (compared with 59.3% in Poland and 64.6% in Europe), 508 (51%) were unemployed                                                                                                                                                                                                | 995 PwE (18-65 yrs), 179 neurologists, and a representative sample of the Polish population over 15 yrs of age (1042) | Lower rate of employment           |
| Prospective and longitudinal long-term employment outcomes after resective epilepsy surgery                  | Edelvik             | 2015 | Sweden  | longitudinal study | Full-time work 33.5% at 2 years 35.5% at 5 years 35.0% at 10 years 32.1% at 15 years. Part-time work 17.9% 17.1% 17.7% 25.0%<br>Student 11.3% 11.1% 11.8% 6.0%<br>Benefits/unemployed 35.3% 34.1% 32.5% 34.5% (rates reported were at 2-5-10 years of FUP) In the general population, 65% to 71% (25-54 years old) | 473 PwE (85 complete FUP)                                                                                             | Lower rate of employment           |

**Table 2 Papers reporting different rates of employment/unemployment.**

## **Employment status and unemployment rate**

Unemployment rates reported among PwE were different around Europe.

Here we list articles comparing rates of employment/unemployment with the general population, in chronological order (Table 1 and 2).

Scambler in 1980, interviewing adults with epilepsy, described the following employment situation in the UK: 31/42 (74%) of men in working age, 6/19 (32%) of married women and 5/12 (42%) of unmarried women were employed, with respective rates in the general population: 81% (men), 48% (married women), and 42% (unmarried women) [21].

Several studies conducted by Ann Jacoby et al. analysed the employment situation in the UK in the 90s, both from the employers' and employees' perspective [9], [22], [23]. Among those studies, in 1992 and 1995, she demonstrated a similar rate of employment in people with well-controlled epilepsy compared to the general population. In 1992, rates reported among PwE were 91% of men and 74% of women under 60 employed; of those unemployed only 3% reported epilepsy as the main reason [22]. Similar results were described in 1995: among 494 PwE at working age 71% were employed, 26% unemployed and 3% of those unemployed reported seizures as the reason for unemployment [23]. Collings reported a rate of unemployment of 12% compared to the 9% national unemployment rate in the UK in 1994 [8].

In 1992, Callaghan described the employment situation in Ireland in a population of 343 PwE: 34% of males and 28% of females were unemployed; 53% of males and 24% of females were gainfully employed; 1% of males and 41% of females did house duties; 8% of males and 7% of females were involved in sheltered employment; 4% of males and <1% of females were retired. They also highlighted higher underemployment among PwE (34%) compared with the general population (13%) in the same years [24].

On the contrary, Kourchonov evidenced a lower rate of employment in PwE in Germany, despite the promulgation of the Law on Support of Employment in 1996[25].

In more recent years, Herodes and Rätsepp both demonstrated similar rates of unemployment compared to the general population in Estonia [26], [27].

Geerts reported similar rates of employment among people with childhood onset epilepsy compared to the general Dutch population in a longitudinal study, regardless the specific kind of epilepsy: idiopathic epilepsy 91.5%, symptomatic epilepsy 91.3%, cryptogenic epilepsy 97.1%, epilepsy in remission 93.2%, active epilepsy 91.2%, all compared with Dutch age peers 92% [28].

A cross-sectional multicentric epidemiological study in Spain also showed similar rates of employment and unemployment in PwE compared to the general population[4]

Recently in Poland, Majkowska demonstrated lower rates of employment in PwE (49%) compared to the Polish and European populations (59.3% and 64.6%, respectively) [29].

As for surgical patients, Edelvik compared the employment rate of seizure-free patients after surgery in a prospective longitudinal study. In the Swedish general population, 65% to 71% of those between 25 and 54 worked full-time, compared to the 36% in seizure-free patients 5 years after surgery and the 65% 10 years after surgery [30].

Considering surgical treatment outcomes, Reinholdson showed that seizure-free PwE with intelligence quotient (IQ) >70 gain the same level of employment as the general population [31].

In the last decades (2000-2023), a slight prevalence of articles reporting similar rates of employment (five vs three) has emerged.

## Factors contributing to unemployment and underemployment

Unemployment and underemployment in PwE derive from a combination of multiple and different factors. Internal factors include individual characteristics, clinical features, and self-concepts. Work atmosphere, knowledge, employers' attitudes represent the main external determinants of employment status (Table 3)[2].

| FACTORS            | Employment                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    | Unemployment                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|--------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Individual factors | <p><b>Seizure control and remission</b><br/>(Sorel 1972; McLellan 1987; Collings 1994; Jacoby 1995; Jacoby 1996; Chaplin 1998; The REST-1 Group; Dupont 2006; Sillanpaa 2010; Jennum 2011; Schulz 2013; Majkowska-Zwolinska 2012; Edelvik 2015; Walther 2018)</p> <p><b>Ongoing treatment with lower number of antiseizure medications</b><br/>(DeBoer 2005; Haag 2010; Jennum 2011; Marinas 2011; Korchounov 2012; Schneider-von Podewils 2014)</p> <p><b>Surgery</b><br/>(Dupont 2006; Carreño 2008; Walther 2018)</p> <p><b>Normal IQ and cognitive function</b><br/>(Sillanpaa 2010; Reinholdson 2019; Partanen 2022)</p> | <p><b>Early onset</b><br/>(Pond 1960; Herodes 2001; Jacoby 2005; Geerts 2011; Walther 2018; Jennum 2020)</p> <p><b>Seizure severity, type &amp; frequency</b><br/>(Scambler 1980; Jacoby 1992; Callaghan 1992; Jacoby 1995; Jacoby 1996; Ratseep 2000; Herodes 2001; De Boer 2005; Jacoby 2005; Koponen 2007; Marinas 2011; Schneider-von Podewils 2014; Walther 2018; Reinholdson 2019; Mireia 2021)</p> <p><b>Cognitive deficits</b><br/>(Gordon &amp; Russel 1958; Thompson 1988; Geerlings 2015)</p> <p><b>Psychiatric comorbidities</b><br/>(Pond 1960; Gloag 1985; McLellan 1987; Jacoby 1996; Peña 2008; Jennum 2011; Mireia 2021)</p> |
|                    | External factors                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | <p><b>Training and job counselling</b><br/>(Sorel 1972; Carroll 1992; Chaplin 1998)</p> <p><b>Higher education</b><br/>(Collings 1994; Ratseep 2000; Herodes 2001; Koponen 2007; Majkowska-Zwolinska 2012; Edelvik 2015)</p> <p><b>Favourable atmosphere at work and positive individual perception</b><br/>(Graham 1965; Collings 1994; Jacoby 2005)</p>                                                                                                                                                                                                                                                                                     |

**Table 3 Most relevant internal and external factors contributing to employment and unemployment among PwE (more than 3 articles reporting)**

### Individual factors

Among individual factors, younger age and early onset of disease seem to negatively affect the chance of obtaining a good job position [27], [32], [33]. Other studies confirm these results: in a Finnish study, Sillanpaa evidenced that onset at age >6 is one factor promoting employment in PwE [34]. According to Geerts, childhood-onset epilepsy is strictly connected to lower educational success, and so to a lower job attainment [28]. On the other hand, Haag found that older people had a lower probability of being employed [35]. Jacoby demonstrated comparable results in a large cohort study in the UK in 1996 [36].

Another relevant element is cognition: cognitive deficit and intellectual constraints consistently impair job attainment [37], [38], [39]. Academic difficulties and lower educational levels also contribute to unemployment [40], [41]. Social difficulties [42]

and psychiatric comorbidities [43], [44], as anxiety and depression [23], [40], [41], [45], might also impair employment.

### **Clinical factors**

When considering clinical factors, the most important determinants of employment are seizure freedom and remission. Multiple studies indicated seizure severity as the main explanation for unemployment in PwE. In 1992, Jacoby, focusing on a population of well-controlled PwE, stated that active epilepsy (seizures occurring in the last 2 years) impaired employment conditions [22]. Three years later, the same group established in a similar population that seizure severity, frequency, and controllability negatively affect employment in PwE [23]. Refractory epilepsy may hamper long-term social outcomes, including employment [4]. Conversely, seizure remission and having no history of status epilepticus are positive factors in people with childhood-onset epilepsy [46] Later, other authors asserted that a higher seizure frequency was linked to unemployment [21], [23], [26], [27], [31], [39], [47]. When considering long-term outcomes, treatment with anti-seizure medications (ASMs) prompts seizure control and, in most cases, seizure freedom; thus, it can be considered as another clinical factor connected to employment [44], [48]. Seizure type can also influence employment: tonic-clonic seizures are linked to a worse employment status [23], [48].

In general, comorbid disabilities lead to lower educational levels and chances of employment, as demonstrated in a population of surgical patients in Germany[49]. Polytherapy also affects employment status and quality of life [4], [50]. Clearly, a higher number of drugs can affect cognitive capacities and concentration, and so, the ability to work normally.

### **Impact of Misconceptions and misbeliefs**

Stigma, misconceptions and misbeliefs surrounding epilepsy lead to discrimination from employers and self-denial of employees in the workplace [21], [42], [47]. Employers' attitudes and unsupportive familial environment can hamper gaining a good job position [9], [38], [51], [52]. Limits posed by specific work issues, such as working with machinery or driving license restrictions, can affect employment status in PwE [51], [53].

To summarize, we can refer to Gloag's paper in which he highlighted three aspects impairing job position in PwE: the hazards posed by specific jobs in case of seizures; anxiety and prejudice on the side of employers and fellow workers; and behavioural and mental abnormalities [10]. Geerlings has also drawn a specific predicting risk profile score made up of unsupportive family environment, lower intelligence, higher seizure frequency, and ongoing seizures [39].

### **Underemployment and lower salaries**

Researchers have shown evidence of disadvantages for PwE in the workplace, even when a higher rate of unemployment is not reported. PwE earned lower salaries [16], [44] and were underemployed compared to the general population [24], [54], [55]. These issues may derive from lower educational levels [56], employers' attitudes, misconceptions, and self-denial.

### **Factors favouring employment**

Factors opposed to those previously described facilitate employment. The most reported factor favouring employment is seizure remission or good seizure control [8], [29], [34], [47], [57].

People with normal intelligence are prone to get a better education and, consequently, better employment [46], [58], [59]. Focusing on specific functions, Partanen demonstrated that better working memory and executive functions were associated with improvement in employment status in surgical patients [60].

A higher educational level allows PwE to reach a more suitable job [27], [30], [61], [62], [63].

Experiences from Ireland, the UK and Belgium demonstrated that training and job counselling favoured employment of PwE more than other elements [47], [59], [64].

Having a favourable atmosphere at work, strong relationships and a positive individual perception increase the chances of being employed [8], [63].

Although social aspects are less explored, we can assume that emotional stability (also having no psychiatric comorbidities) and proper social skills positively contribute to PwE employment status [42].

As declared before, employment status is strictly connected to seizure control and seizure freedom [40], [47], [49], [59], [65], [66], [67]. Other clinical factors such as being treated with a lower number of ASMs can contribute to a good employment situation [68]. When considering long-term outcomes, surgery has modest but significant influence on employment status in surgical candidates [66], [69], [70]. Finally, having a driving license also contributes to independence and, hence, improves the employment situation in PwE [53].

Considering external factors, apart from employers' attitudes, promulgation of laws favouring inclusion of PwE in the workplace represents one of the most relevant determinants supporting employment, as proven in Germany [25].

### **Long term outcomes and specific conditions**

When analysing specific conditions:

#### NON-SURGICAL PATIENTS

- In Sweden, Olsson analysed long-term outcomes in people with absence epilepsy. In about 74% of cases, epilepsy impaired social aspects such as schooling, occupation, relationships, regardless of seizure control [54].
- Peña demonstrated worse outcomes in people with higher scores of anxiety and depression in a population of people with refractory epilepsy [71].
- Two studies focused on outcomes of people with childhood-onset epilepsy. Geerts evidenced lower job attainment of people with childhood onset epilepsy, despite remission [56]. Sillanpää demonstrated better employment outcomes in people with normal intelligence, onset of epilepsy >6 years old, good vocational education, uninterrupted remission, and no history of status epilepticus [46].
- Schneider-von Podewils drew the special situation of Janz syndrome (now defined as Juvenile myoclonic epilepsy), specifying that a higher number of generalized seizures was associated with a worse outcome [48].

## SURGICAL PATIENTS

- Reinholdson proved that good surgical outcomes in children, depend on normal intelligence, seizure freedom, and higher age at surgery: people with these features showed higher employment rates [31].
- Partanen in Finland revealed that normal cognitive functions are correlated with better social outcomes after surgery [60]
- Edelvik evaluated long-term outcomes after resective surgery: younger people, seizure-free patients and people employed/studying at baseline develop better employment outcomes [30].
- In cases susceptible to surgical treatment, surgery seems to improve employment status in PwE: we can reach this conclusion comparing outcomes in people who undergo surgery [70] and people who do not [69].
- Extratemporal surgery leads to a better quality of life and, consequently, a better psychosocial outcome, especially in people gaining seizure freedom[66]
- Concerning long-term (>10 years) psychosocial and socioeconomic outcomes of paediatric epilepsy surgery, Hoppe demonstrated that when effective surgery leads PwE to better social outcomes. Also, comorbid disabilities impair employment attainment, whereas seizure freedom improves it. They also underlined the difference in rate of employment for PwE who had unilobar surgery (76%) and PwE who had multilobar surgery (10%) [49].
- Finally, Dupont focused on surgery in Medial Temporal Lobe Epilepsy, demonstrating the intrinsic positive value of surgery on employment status[70].

## **Disclosure issues**

Though it was not our primary aim, we could not leave unmentioned papers that shed light on such a controversial issue as disclosure. Most PwE fear discrimination, stigmatization and negative consequences (such as being fired, demoted, or unemployed) when revealing their condition. They frequently conceal their disorder, especially if well controlled [8], [23], [43]. In different studies, about one-half or one-third of the population examined did not disclose their condition [21], [63], [72]. Lassouw evidenced that in a Dutch working population 77% of respondents disclosed their condition, although they refused to answer questions about the impact of epilepsy on their job [73].

## **Employment programs and interventions for PwE in Europe**

In Europe we found report of a few experiences with inclusion programs. In 1992, Carroll demonstrated the usefulness of a rehabilitation program in the Irish population: 58% of the considered population had found employment at the end of the program. Furthermore, about 66% of the surveyed population thought that programs are useful to develop self-confidence and social skills [64]. Similarly, in Sweden, Wedlund demonstrated improvement in work and education participation in 38 among 124 PwE participating in a rehabilitation program [74].

## **Surveys**

### **Aims and Objectives**

Major factors influencing employment include seizure control and remission, normal cognitive function and absence of psychiatric comorbidities, higher education, and a favourable atmosphere at work and in the family. Indeed, spreading awareness and knowledge about epilepsy could help improve employment conditions among PwE[75].

In connection with the results from the literature and the lack of sufficient information by official sources on crucial aspects regarding the employment of PwE, we realised two specific surveys for each target group of the project. The first target group of the project included PwE, whereas the second one Higher education institution (HEI) staff and end-users: professors, university staff, placement officers, students, entrepreneurs/managers attending MBA/Executive courses, adult people employed in organisations, recruiters, HR experts and recruitment agencies. PwE survey was developed to explore employment opportunities and experiences of PwE in the workplace; the one for HEI concerned general knowledge about epilepsy and the individual relationship with PwE.

### **Survey Methods**

We used SurveyMonkey (SurveyMonkey Inc.) to develop two anonymous surveys. Each survey has been created in English and then translated into each partner's specific language: Italian, French, Deutsch, and Bulgarian.

We collected responses from January 2023 to December 2023. We shared surveys, sending emails, and using official channels of ILAE Chapter (e.g. LICE site) and associations for PwE to promote them. Even for HEI we shared surveys throughout emails or Universities official channels (e.g., UCBM website).

Both surveys included open and closed questions. The survey for PwE was made up of questions about demographic features (age, sex and residing country), clinical data (number of ASMs), seizure frequency, type of seizures, educational and job attainment, issues in the workplace (disclosure, stigma, level of satisfaction).

The survey for HEI was made up of questions about demographic features (age, sex and residing country), understanding of epilepsy and its impact, opinions about unemployment and underemployment, experience with PwE, knowledge of epilepsy and medical aid in case of seizures, support for involvement of PwE.

Data were analysed and represented with Microsoft Excel 2016 (Microsoft Corporation, Redmond, WA, NY). Frequencies were reported as numbers or percentages. Since no personal information was collected, no specific mechanisms to protect unauthorized access were necessary.

### **Surveys Results - Overall questions**

We collected a total of 567 responses from PwE (183 from Italy, 38 from Ireland, 123 from France, 25 from Germany and 198 from Bulgaria).

We collected a total of 291 answers from HEI (100 from Italy, 14 from Ireland, 67 from France, 10 from Germany and 100 from Bulgaria).

In both cases Italy and Bulgaria had the highest number of answers, thus we have considered them as the most reliable samples. Due to the heterogeneity of samples and missed answers (“skipped”) we have decided to describe data without conducting any statistical analysis. We could not conduct analysis since samples had different dimensions, with great cross-country differences and some questions had a great proportion of “skipped” answers.

## PwE surveys

As regards PwE we received a total of 567 complete answers: 183 Italy, 38 Ireland, 123 France, 25 Germany and 198 Bulgaria.

Total number of questions was 22: 16 with closed answers, 6 with open answers.

We have asked questions about demographic factors including age, sex, and geographic provenience (Table 4, Figure 2).

Most respondents were women (62,3%) and aged more than 40 years old (26,6%), in all countries.

In the following map we observe the geographic distribution of received answers: Italy 183; Ireland 31; Belgium 5; Bulgaria 192; France 113; Swiss 2; Austria 1; Germany 23; Denmark 1; Greece 2; Estonia 1; Non-EU Country 11 (Georgia 1; Bosnia Herzegovina 1; Turkey 1; other countries 7).

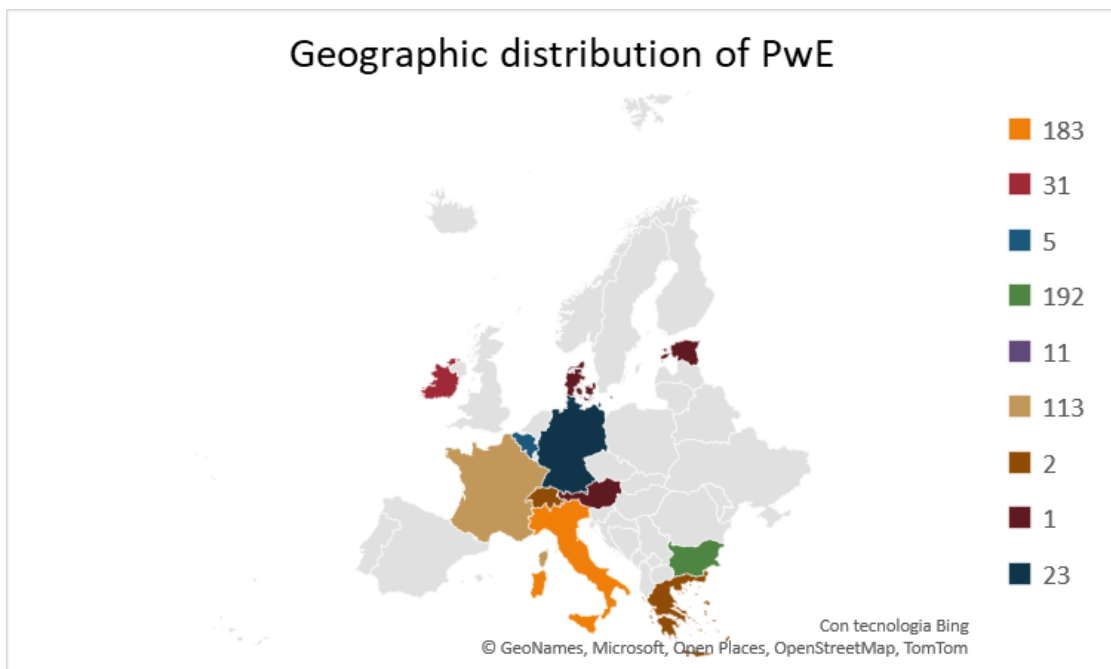


Figure 2 Geographic distribution of respondents among PwE

| Age                        | ITALY | IRELAND | FRANCE | GERMANY | BULGARIA | TOTAL |
|----------------------------|-------|---------|--------|---------|----------|-------|
| <b>&lt;20 years</b>        | 4     | 1       | 22     | 3       | 27       | 57    |
| <b>20-29</b>               | 42    | 4       | 32     | 12      | 36       | 126   |
| <b>30-39</b>               | 32    | 8       | 27     | 6       | 51       | 124   |
| <b>40-49</b>               | 33    | 13      | 21     | 2       | 40       | 109   |
| <b>&gt;50</b>              | 72    | 12      | 21     | 2       | 44       | 151   |
| <b>TOTAL</b>               | 183   | 38      | 123    | 25      | 198      | 567   |
| <b>Sex</b>                 |       |         |        |         |          |       |
| <b>Male</b>                | 70    | 10      | 38     | 8       | 77       | 203   |
| <b>Female</b>              | 113   | 28      | 83     | 17      | 112      | 353   |
| <b>I prefer not to say</b> | 0     | 0       | 2      | 0       | 9        | 11    |
| <b>TOTAL</b>               | 183   | 38      | 123    | 25      | 198      | 567   |

Table 4 Age and sex of respondents

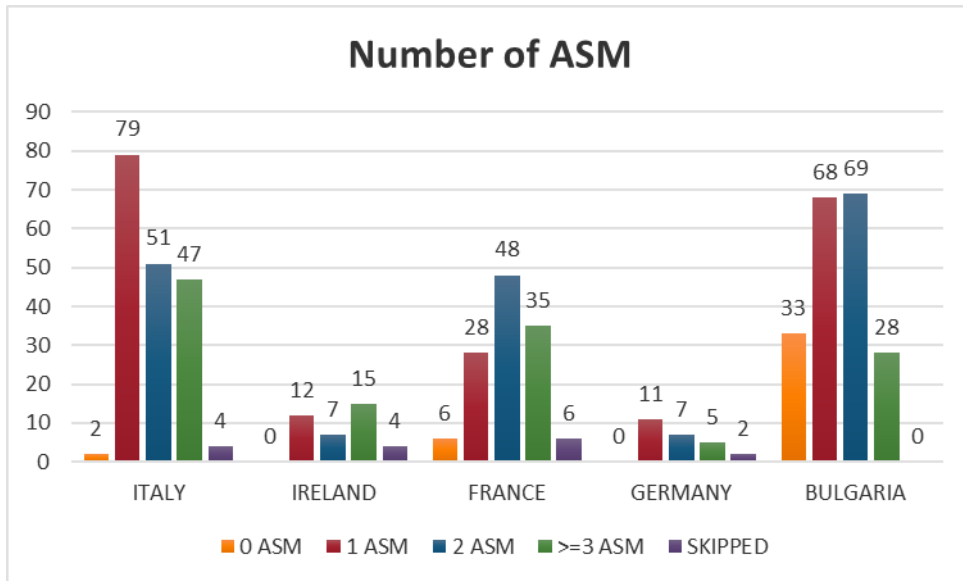
Concerning clinical features, we asked about:

- age of onset
- number of ASMs taken
- seizure freedom
- number of seizures (total – focal and generalized) in the last three months.

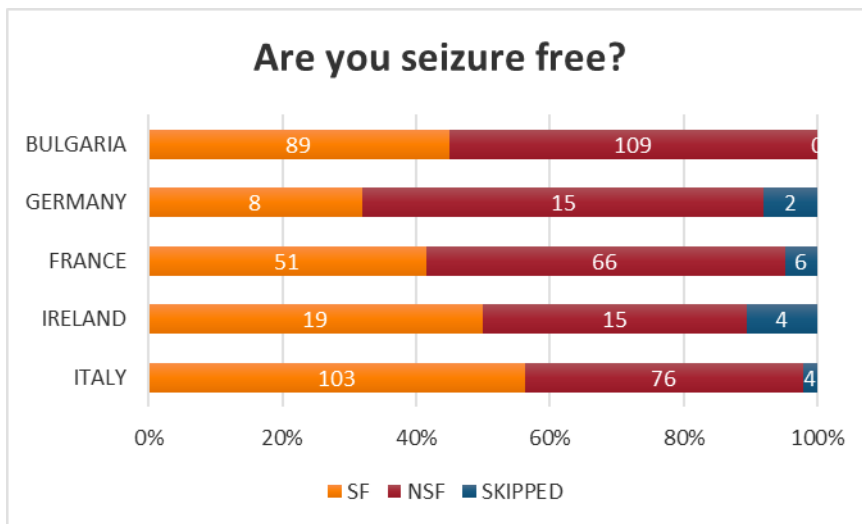
As regards age of onset you can see the mean age of onset for respondents in each country in the table below (Table 5).

| Country         | Mean  | Std deviation |
|-----------------|-------|---------------|
| <b>ITALY</b>    | 25,19 | 17,54         |
| <b>IRELAND</b>  | 20,68 | 14,99         |
| <b>FRANCE</b>   | 15,94 | 11,54         |
| <b>GERMANY</b>  | 15,04 | 9,06          |
| <b>BULGARIA</b> | 16,55 | 11,02         |

Table 5 Mean age of onset of epilepsy among PwE respondents



**Figure 3** Number of ASMs taken by respondents in each country



**Figure 4** Average of seizure-free and not seizure free PwE

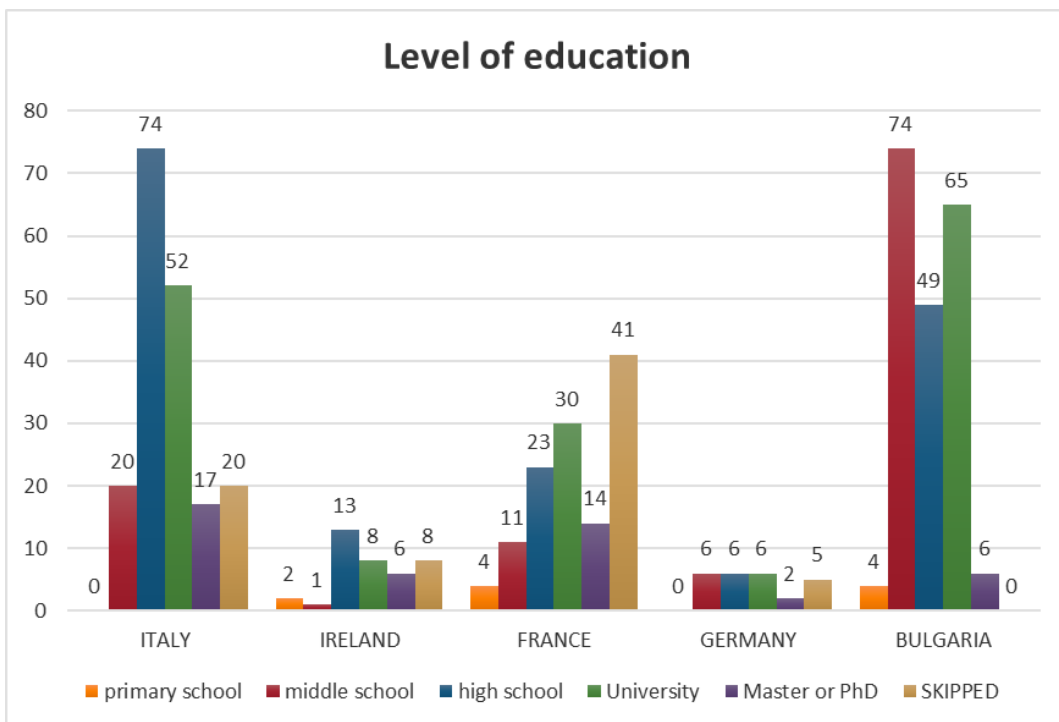
Averages of people not seizure free were: 42% in Italy, 39% in Ireland, 54% in France, 60% in Germany and 55% in Bulgaria.

In Table 6, we have listed the mean of total seizures (focal and generalized) in the last 3 months:

| Country  | MEAN  | ST DEV |
|----------|-------|--------|
| ITALY    | 13,04 | 24,58  |
| IRELAND  | 27,86 | 45,03  |
| FRANCE   | 44,63 | 225,10 |
| GERMANY  | 28,54 | 47,54  |
| BULGARIA | 0,20  | 0,59   |

**Table 6 Mean number of seizures in the last 3 months with standard deviation**

Our intention was to investigate the level of employment and, consequently, we have explored educational and job attainment.



**Figure 5 Level of educational attainment of PwE**

As you can see in figure 5, most of the respondents have reached at least a high school degree in Italy, whereas in Bulgaria most of the respondents (37,4%) completed middle

school. Average of respondents needing extra-support are listed in table 7: about a third of the population needed support in France, Germany and Bulgaria.

| Did you need extra-support at school? | Italy      |       | Ireland    |       | France     |       | Germany    |       | Bulgaria   |       |
|---------------------------------------|------------|-------|------------|-------|------------|-------|------------|-------|------------|-------|
|                                       | Percentage | Count | Percentage | Count | Percentage | Count | Percentage | Count | Percentage | Count |
| Yes                                   | 7,9%       | 13    | 40%        | 12    | 29,3%      | 24    | 35%        | 7     | 32,8%      | 65    |
| No                                    | 92%        | 150   | 60%        | 18    | 70,7%      | 58    | 65%        | 13    | 67,2%      | 133   |
| Answered                              |            | 163   |            | 30    |            | 82    |            | 20    |            | 198   |
| Skipped                               |            | 20    |            | 8     |            | 41    |            | 5     |            | 0     |

Table 7 PwE who needed extra support at school.

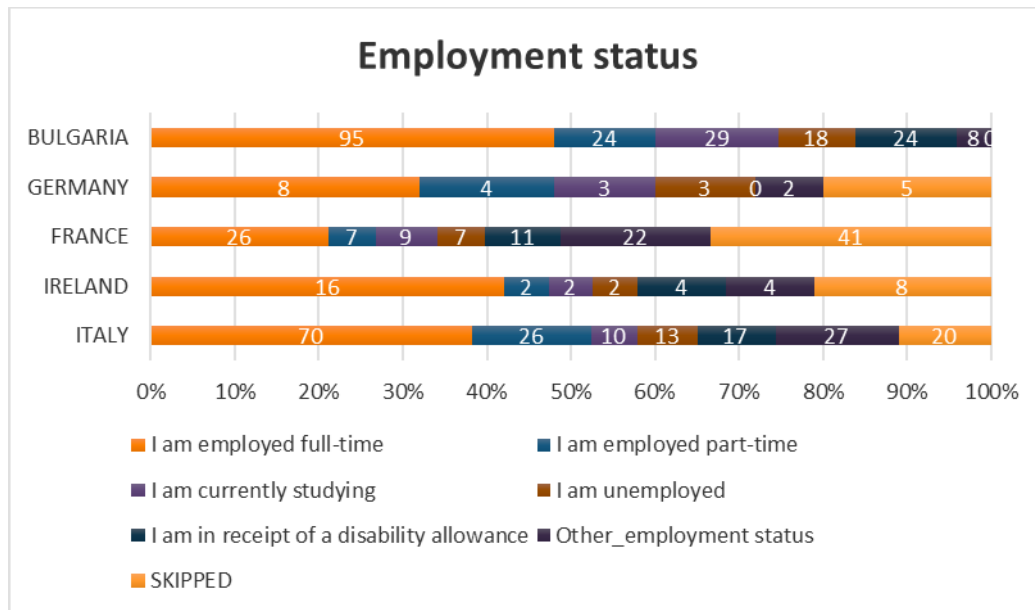


Figure 6 Employment status among PwE

Rates of unemployment registered were 7,9% in Italy, 6,7% in Ireland, 8,5% in France, 15% in Germany, 9% in Bulgaria. In comparison, the reported rates of unemployment in the general population in the same year (2023) were Italy: 7.7%; Ireland: 4.2%; France: 7.5%; Germany: 6.3%; Bulgaria: 4.5% (Figure 6) [76], [77], [78], [79], [80].

We have also asked about current salary with actual job position: a big slice of Bulgarian PwE (148) earned less than 15000 €.

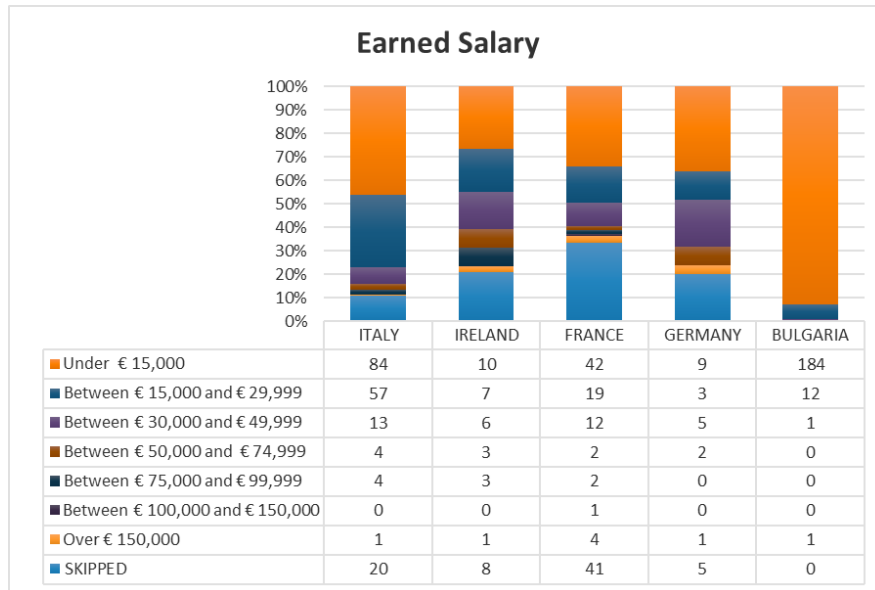


Figure 7 Salaries earned by PwE

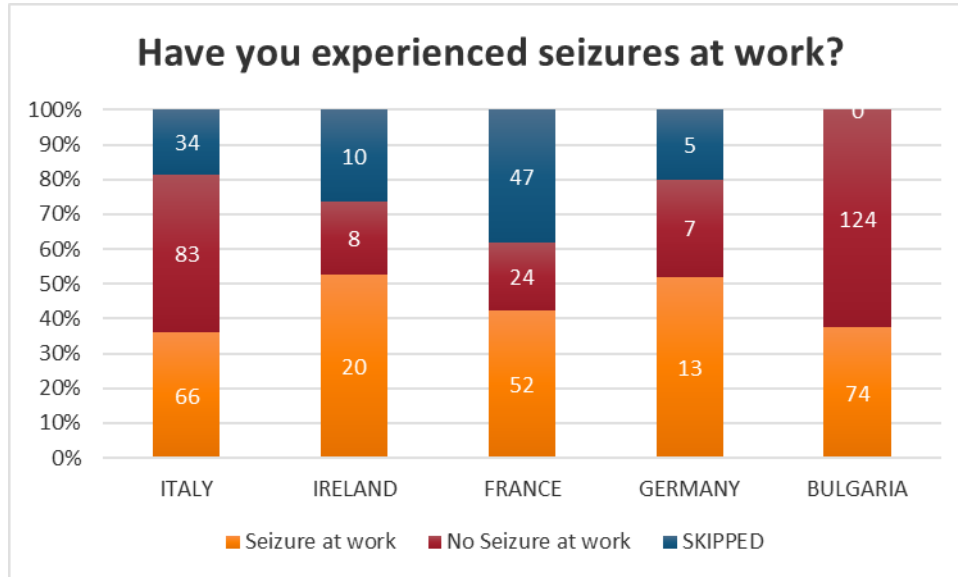
| Country  | OECD 2023 average wage (USD PPP)        | OECD equivalent in euros | Dominant salary band in your sample | Comparison                      |
|----------|-----------------------------------------|--------------------------|-------------------------------------|---------------------------------|
| Italy    | 36,658                                  | ~33,700 €                | Under 15,000 €                      | Much lower than OECD level      |
| Ireland  | 49,474                                  | ~45,500 €                | Under 15,000 €                      | Extremely lower than OECD level |
| France   | 43,755                                  | ~40,300 €                | Under 15,000 €                      | Much lower than OECD level      |
| Germany  | 53,745                                  | ~49,400 €                | Under 15,000 €                      | Extremely lower than OECD level |
| Bulgaria | ~14,700 USD PPP (Eurostat/OECD aligned) | ~13,500 €                | Under 15,000 €                      | Consistent with OECD level      |

Table 8 Comparison with Organization for Economic Co-operation and Development (OECD) salaries for 2023

In Table 8, we have compared dominant salary group of specific population with Organization for Economic Co-operation and Development reported salaries. In Italy, Ireland, France and Germany, the majority of respondents fall into the lowest salary band (<15,000 €), far below national OECD averages that range from ~33,700 € to ~49,400 €. Bulgaria is the only country where the sample aligns with national salary

expectations, as the OECD/EU average is close to 13,500 €, matching the dominant band in our data.

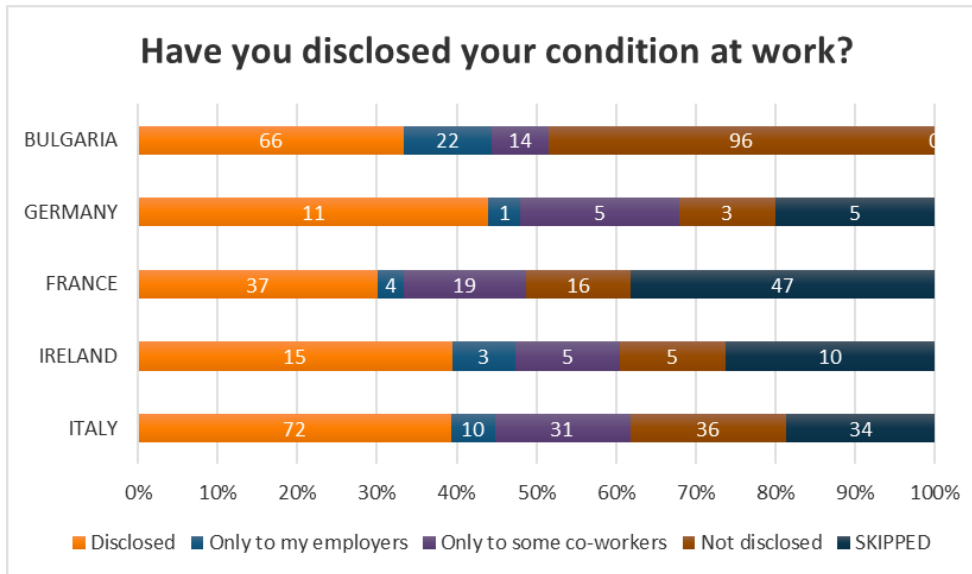
As regards epilepsy in the job place, we examined if PwE had experienced seizures at work and if they disclosed their condition at work (Figure 8).



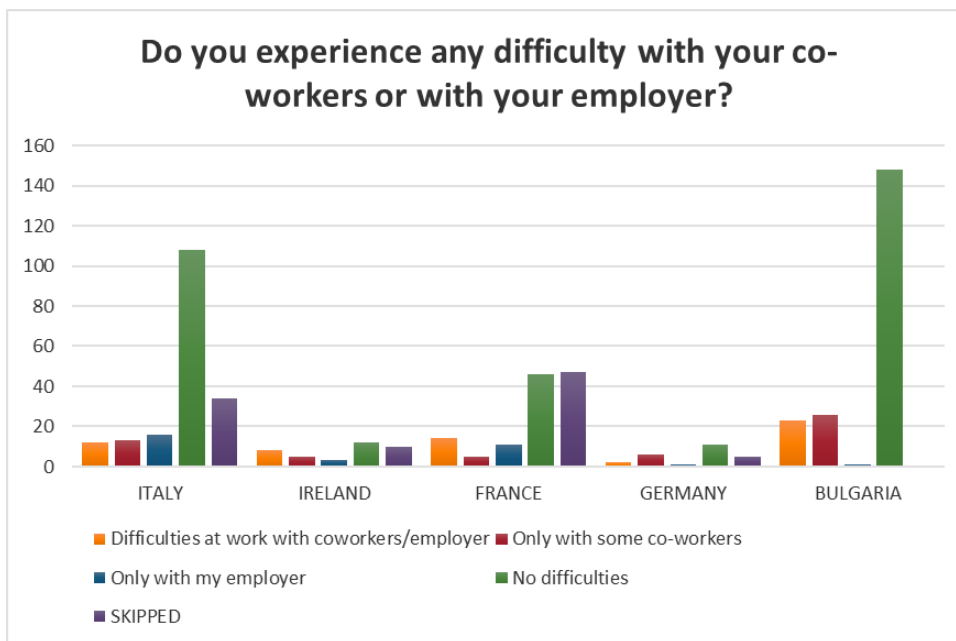
**Figure 8 Rate of PwE who have experienced seizures in the workplace**

As you can see in figure 8, the 36% of Italian PwE and the 37% of Bulgarian PwE have experienced any seizure at work. For Ireland, France, and Germany, these rates were 52%, 42%, and 52% respectively.

Although almost one third of PwE have experienced seizures at work, a percentage of 19% in Italy did not disclose their condition at work; 13% in Ireland, 13% in France; 12% in Germany and 48,5% in Bulgaria (Figure 9).



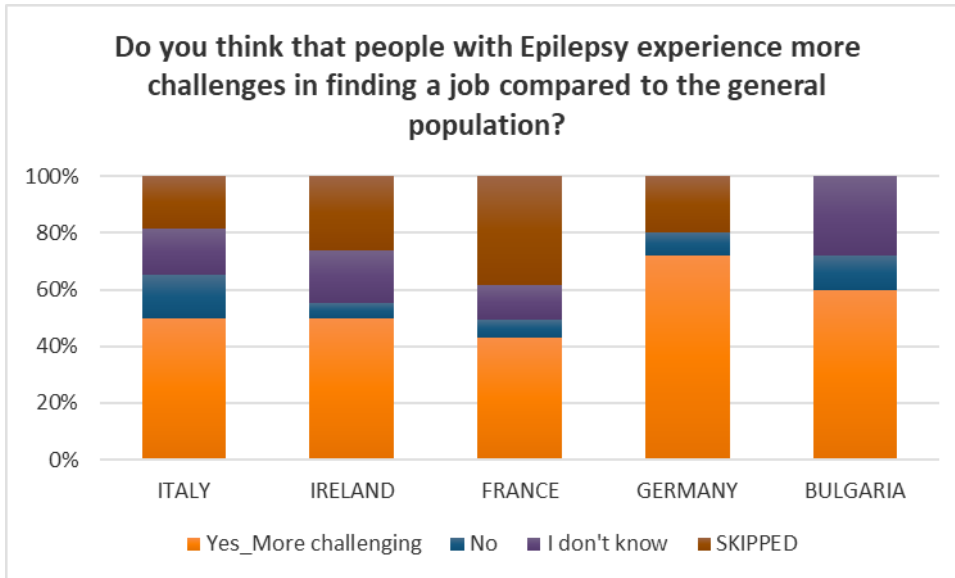
**Figure 9 Rates of PwE who disclosed epilepsy in the workplace**



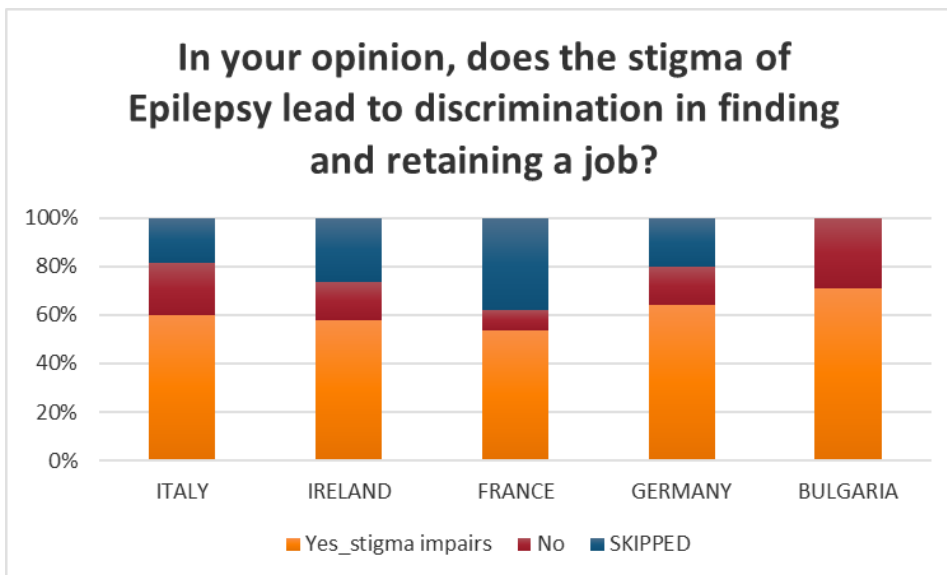
**Figure 10 Average of PwE with difficulties at work**

Most PwE generally declared that they have not experienced any difficulty in the work environment (Figure 10). We have asked if they think that challenges and stigma still impair finding and retaining a job for PwE. Unsurprisingly, as regards experiencing more challenges at work, in Italy the 49%, in Ireland the 50%, in France the 43%, in Germany the 72% and in Bulgaria the 59% thought that PwE experience more challenges in finding a job (Figure 11).

When asking about stigma, in Italy the 60%, in Ireland the 57%, in France the 54%, in Germany the 64% and in Bulgaria the 71% of respondents thought that stigma prompts discrimination in finding and retaining a job (Figure 12).



**Figure 11** Rate of PwE thinking that PwE experience more challenges in finding a job



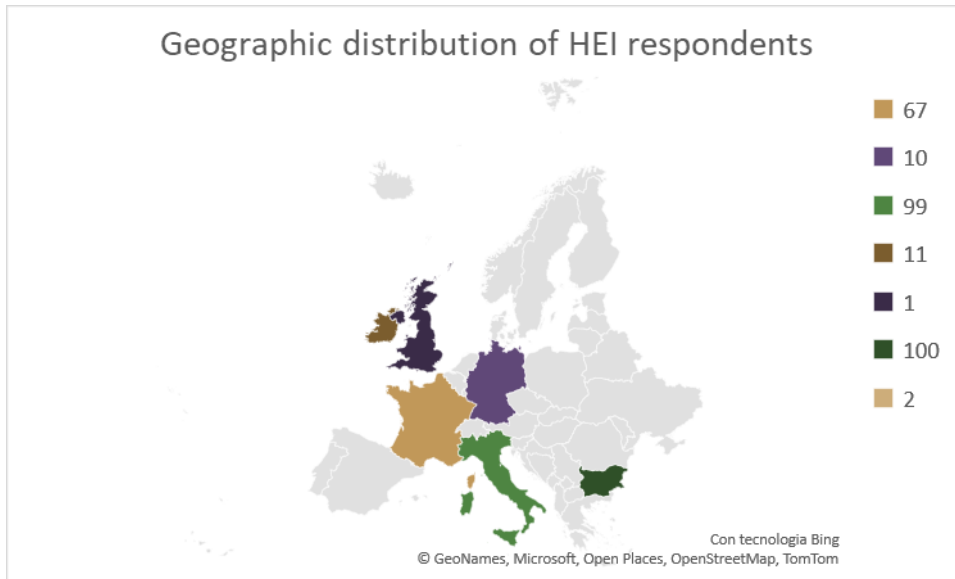
**Figure 12** Average of PwE thinking that stigma impairs finding and retaining a job

## HEI surveys

As regards HEI, we have collected a total of 291 answers: 100 Italy, 14 Ireland, 67 France, 10 Germany, 100 Bulgaria. Total number of questions was 16: 15 closed and 1 open question. In the first section, we asked questions about demographic factors such as age, sex, and geographic distribution (Table 9, Figure 13).

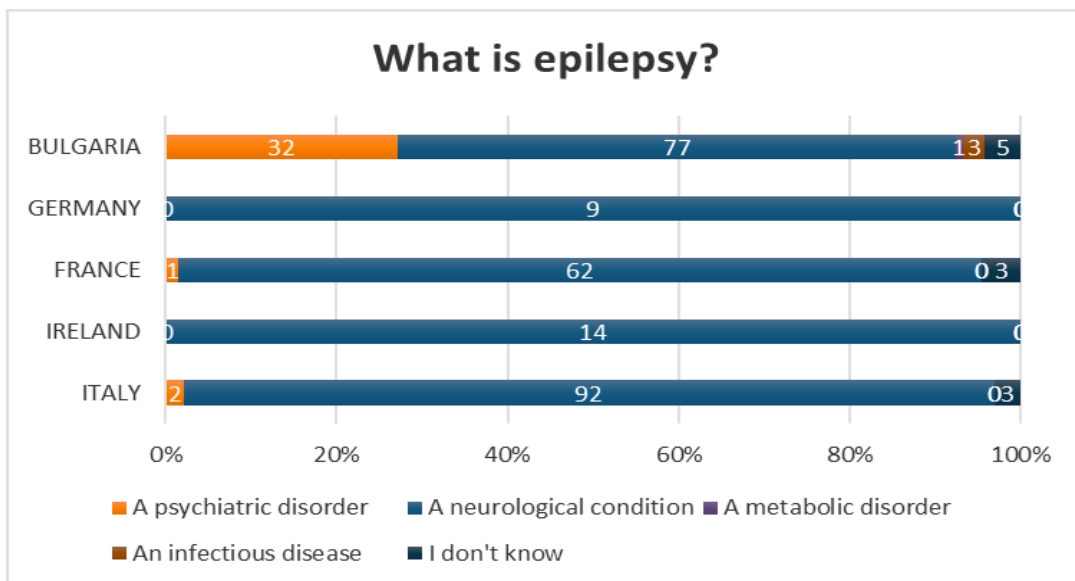
| Age                            | ITALY | IRELAND | FRANCE | GERMANY | BULGARIA |
|--------------------------------|-------|---------|--------|---------|----------|
| <20 years                      | 1     | 1       | 0      | 0       | 13       |
| 20 – 29                        | 9     | 4       | 1      | 1       | 18       |
| 30 – 39                        | 28    | 2       | 16     | 4       | 25       |
| 40 – 49                        | 25    | 3       | 18     | 0       | 25       |
| > 50                           | 37    | 4       | 32     | 5       | 19       |
| <b>TOTAL</b>                   | 100   | 14      | 67     | 10      | 100      |
| <b>Sex</b>                     |       |         |        |         |          |
| <b>Male</b>                    | 26    | 5       | 10     | 4       | 45       |
| <b>Female</b>                  | 73    | 9       | 55     | 5       | 53       |
| <b>I prefer not specifying</b> | 1     | 0       | 2      | 1       | 2        |
| <b>TOTAL</b>                   | 100   | 14      | 67     | 10      | 100      |

Table 9 Age and sex distribution among HEI



**Figure 13 Geographic distribution of HEI respondents**

We asked to higher educational institutions workers what kind of disease epilepsy is and if it is treatable:



**Figure 14 HEI opinions about the nature of epilepsy**

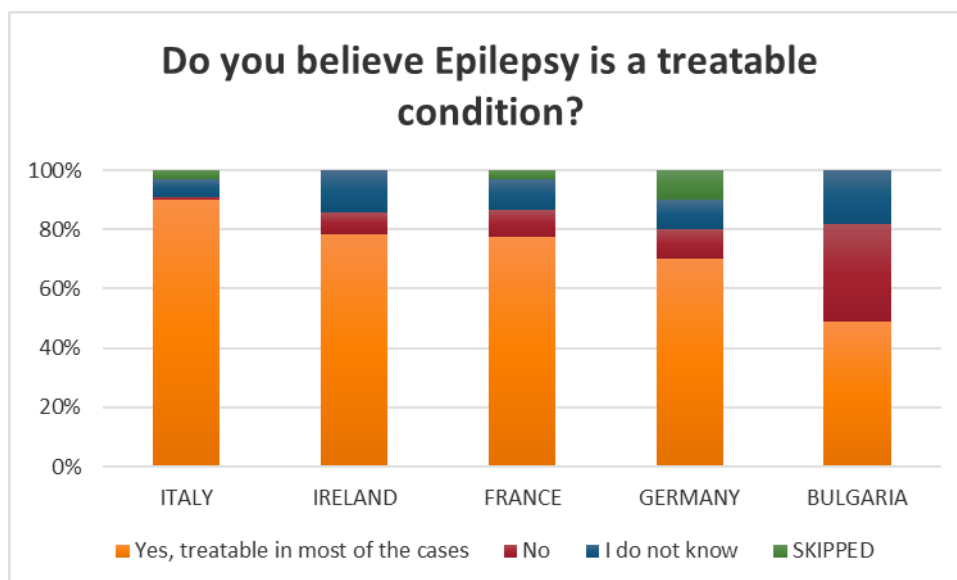


Figure 15 Answers regarding the possibility of treating epilepsy from HEI perspective.

| What is epilepsy?                                        | ITALY | IRELAND | FRANCE | GERMANY | BULGARIA |
|----------------------------------------------------------|-------|---------|--------|---------|----------|
| <b>A psychiatric disorder</b>                            | 2     | 0       | 1      | 0       | 32       |
| <b>A neurological condition</b>                          | 92    | 14      | 62     | 9       | 77       |
| <b>A metabolic disorder</b>                              | 0     | 0       | 0      | 0       | 1        |
| <b>An infectious disease</b>                             | 0     | 0       | 0      | 0       | 3        |
| <b>I don't know</b>                                      | 3     | 0       | 3      | 0       | 5        |
| <b>SKIPPED</b>                                           | 3     | 0       | 2      | 1       | 0        |
| <b>Do you believe Epilepsy is a treatable condition?</b> |       |         |        |         |          |
| <b>Yes, treatable in most cases</b>                      | 90    | 11      | 52     | 7       | 49       |
| <b>No</b>                                                | 1     | 1       | 6      | 1       | 33       |
| <b>I do not know</b>                                     | 6     | 2       | 7      | 1       | 18       |
| <b>SKIPPED</b>                                           | 3     | 0       | 2      | 1       | 0        |

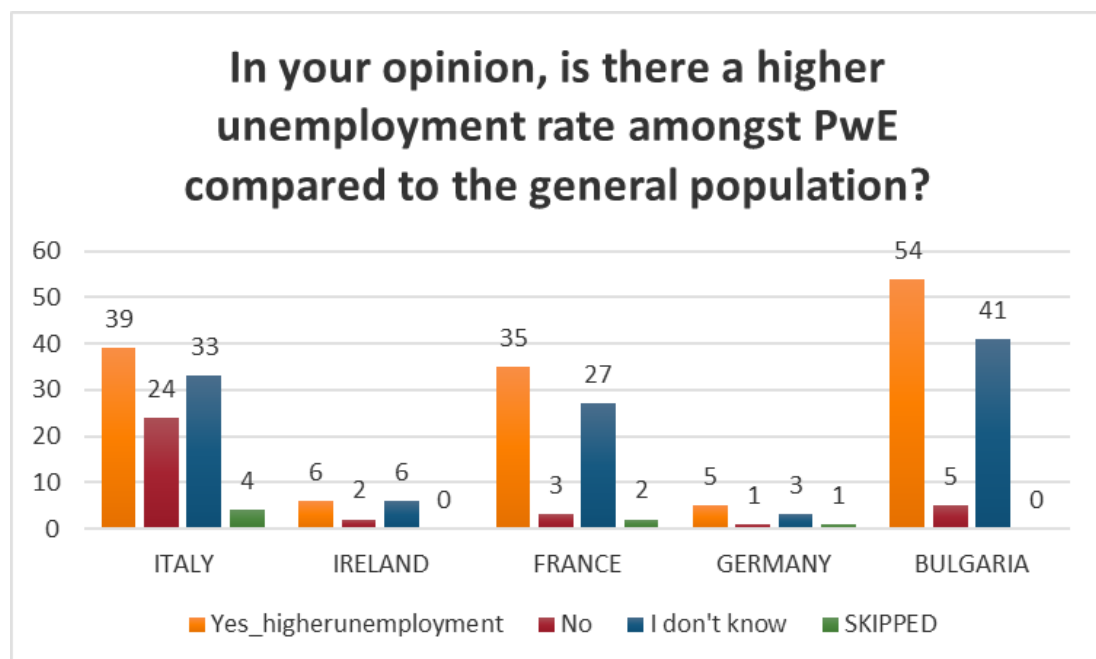
Table 10 Answers regarding epilepsy and the possibility of treating it

As shown in figures 14 and 15, most respondents defined epilepsy as a neurological condition in all countries, and they all agreed that it is treatable in most cases.

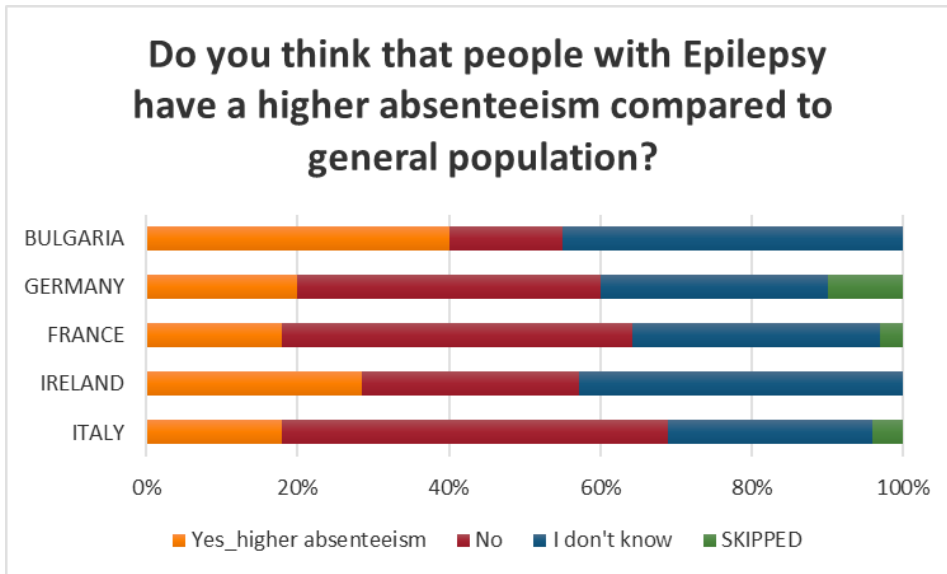
In Italy 92%, in Ireland 100%, France 93%, Germany 90%, and Bulgaria 77% of people correctly defined epilepsy as a neurological condition. The 32% of Bulgarian HEI defining epilepsy as a psychiatric disorder represent an exception (Table 10).

We asked HEI opinion about opportunities, unemployment, and absenteeism among PwE. Some of respondents thought that the unemployment rate is higher in PwE compared to the general population: in Italy and France 18%, in Ireland 29%, in Germany 20% and in Bulgaria 40% of respondents (Figure 16).

On the contrary, most of the respondents thought that the rate of absenteeism is not higher among PwE (Figure 17).

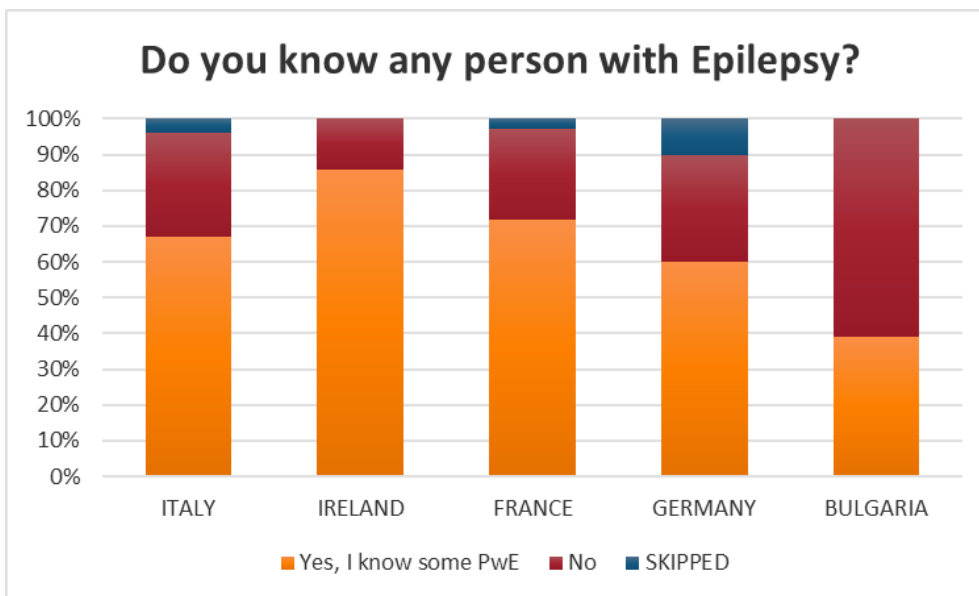


**Figure 16** Questions about level of unemployment among PwE from HEI's perspective



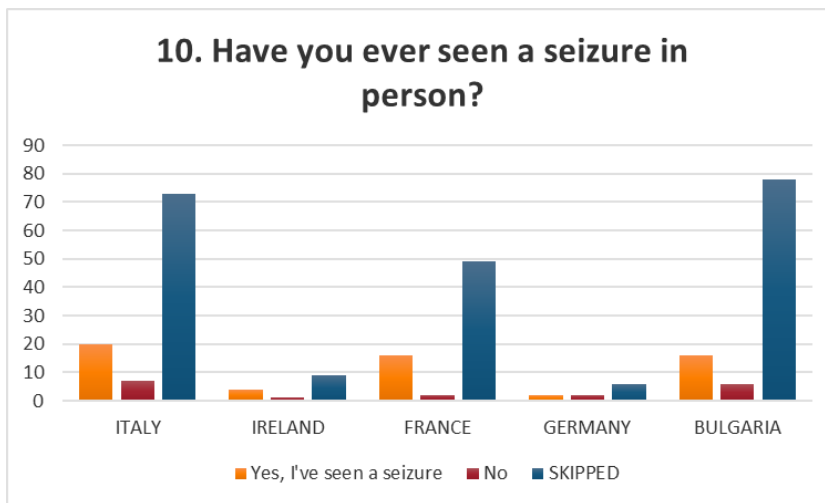
**Figure 17** Level of absenteeism among PwE from HEI's perspective

We have also asked if HEI have known anyone affected by epilepsy and have ever worked with them: 67% in Italy, 86% in Ireland, 72% in France, 60% in Germany and 39% in Bulgaria affirmed that they knew a person with epilepsy (Figure 18).

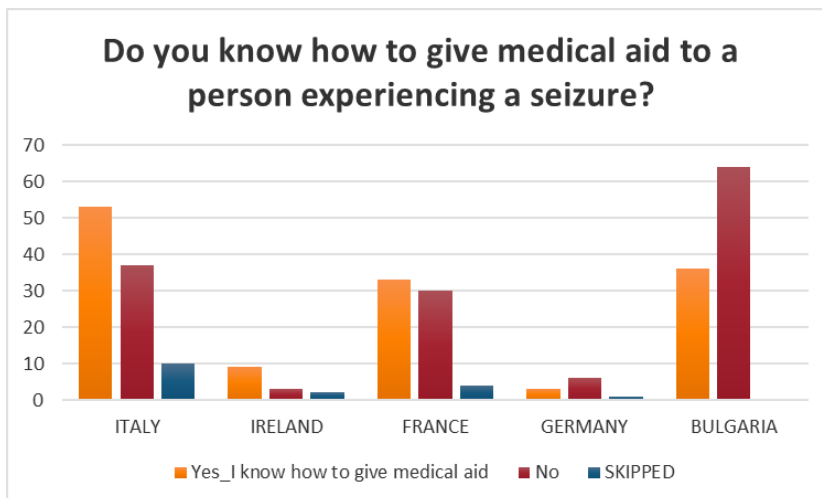


**Figure 18** Number of people among HEI knowing a person with epilepsy.

We have asked if they have ever seen a person experiencing a seizure and if they know how to give medical aid. Most respondents of all countries have skipped the question, but in Italy, France and Bulgaria among respondents the 20%, the 24% and the 16% have seen a seizure in person (Figure 19). In the same countries, the averages of people not knowing how to give medical aid during a seizure were respectively 37%, 45% and 64%. The 53% in Italy, the 49% in France, and the 36% in Bulgaria knew how to help a person with a seizure (Figure 20).



**Figure 19** Number of people among HEI who have ever seen a seizure in person



**Figure 20** Level of knowledge about how to give medical aid during a seizure

Finally, we asked if they receive some money support to employ PwE and most of the respondents declared that they do not receive any economic aid, in all countries: in Italy 58%, in Ireland 29%, in France 45%, in Germany 80% and in Bulgaria 78%.



**Figure 21 Question about economic support received to hire PwE**

## **Final results: learning modules and epilepsy friendly label certificate**

Last result of the project was dedicated to developing two learning paths, trying to fill the knowledge gap for HEI and help PwE with job application and choice. We utilized Delphi method, consulting four expert neurologists (GA, FN, DW, GB) to define relevant topics to explore for PwE and HEI.

The first learning path was dedicated to PwE and included some chapters about self-assessment, job choice, and interaction with co-workers. The second path focused on companies' perspective when hiring individuals affected by epilepsy. As for the rest of the project, we have translated each module in each partner language (Italian, French, Bulgarian, Deutsch). More details of each module can be consulted on the website: <https://epilepsypower.indesign.it/>.

Both learning path ended with a final test. After studying the learning modules and completing the test, companies could apply to get Epilepsy-friendly label certification, in order to prove their knowledge and inclusivity for PwE (Figure 22).

For Learning Path 1 (PwE) subsections were:

1. What is Epilepsy?
2. Conducting a Personal Assessment of Epilepsy to Minimize Workplace Risks
3. Tailoring Employment Choices to Individual Medical Conditions
4. Strengthening your job application process
5. Improving job searching strategies
6. Equal opportunities rights for workers with epilepsy
7. Encouraging Interaction between People with Epilepsy and their Co-workers
8. How to self-promote and find work opportunities
9. LP1 Final Test

For Learning Path 2 (HEI) subsections were:

1. What is Epilepsy?
2. Essentials of human resources management
3. Accommodating people with epilepsy in business processes and activities
4. Improving social communication and interaction skills
5. Managing Stress, Anxiety and Frustration for better inclusion
6. Epilepsy and time management
7. Considerations in assigning tasks to people with epilepsy
8. Processes and steps to become an inclusive PwE organization
9. LP2 Final Test

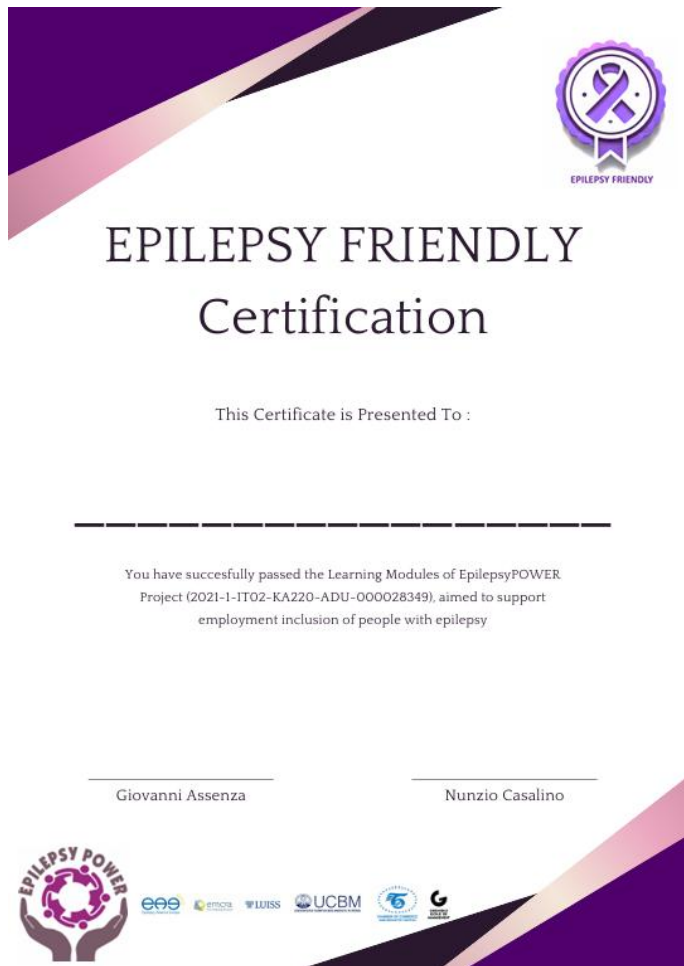


Figure 22 Epilepsy friendly Label certification for companies

## **Discussion**

### **Review**

Our systematic review on employment of PwE resulted in both lights and shadows. Defining the real unemployment rate among PwE remains difficult, since reported rates vary widely - from similar to two to three times higher - depending on the countries and years examined. In the last two decades, a slight prevalence of articles reporting similar employment rates (five articles reporting similar rates vs three papers reporting lower rates of employment) is evident, maybe because of increased awareness about epilepsy.

Conflicting results could depend on different ways to consider or define unemployment, with variations found when including/excluding housewives, students, and retired people.

Yet a clear disadvantage emerges from all European studies [55], [63], [70]. PwE frequently face underemployment or disadvantages like lower salaries, because of varied factors: lower educational attainment, lack of protective policies, stigma, misconceptions, and discriminatory employers' attitudes [24], [54], [55], [56], [73], [81].

Among clinical factors, unsurprisingly, seizure control plays a key role and represents the most reported aspect favouring a suitable job position for PwE. Whether achieved through medications or surgery, it enables better outcomes in all social domains, including job, marriage, and quality of life. Seizure-free people can lead a "normal" life without limitations for driving, cognitive functioning, marriage, and employment, especially if they have good social skills [42]. They are able to achieve higher educational levels and fulfilling careers. Thus, for neurologists, healthcare professionals, and PwE alike, achieving seizure freedom is a matter of utmost importance, since it promotes meaningful inclusion in work and society.

Stigma still represents a significant barrier to employment for PwE. Perceived stigma and discriminatory attitudes (both from employers and families) can severely limit job opportunities and quality of life of PwE [82]. Misconceptions and restrictions contribute to stigma, leading PwE to conceal their condition, often out of fear of

discrimination or job loss. This results in a reduction in ambition, emotional stability, and job attainment. The International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE) are actively working to combat stigma and eliminate unjustifiable restrictions on PwE.

Indeed, educational and rehabilitation programs are other relevant tools to truly achieve the desired position, especially in PwE with normal intelligence and absence of psychiatric comorbidities [64], [74].

This review also devotes special attention to one of the challenges PwE face in obtaining a job: disclosure. Many PwE tend to not disclose their condition, unless necessary, fearing underemployment or dismissal due to ignorant prejudices. Actually, most PwE can work safely without experiencing seizures and posing risks for themselves or colleagues, even without adjustments. A supportive and inclusive workplace environment can encourage disclosure and foster trust between employers and employees. The IBE's 2007 leaflet highlights the importance of creating such environments to fight stigma and promote inclusion [83].

To sum up, we can depict the key elements for PwE to obtain an optimal job position: seizure control, normal cognitive functioning, higher educational levels, and supportive atmosphere (both at work and in the family).

## **Surveys**

In line with the review, with our surveys we have tried to provide an updated picture of working condition among PwE and knowledge of epilepsy in five European countries (Italy, Ireland, France, Germany, Bulgaria). Our findings should be interpreted with caution due to heterogeneous sample sizes and varying rates of missing responses ("skipped").

Maintaining the ability to work means a good balance with social, professional, and familial integration for PwE, as well as for the general population [10]. Among the minimal requirements for a normal life and a normal ongoing job, the most relevant factors are seizure control and clinical features. We demonstrated great differences in the number of ASMs and seizure freedom across five countries included. Italian respondents more often follow a monotherapy regimen. In Ireland and Bulgaria, a

larger proportion of PwE required three or more ASMs. Treatment with a higher number of ASMs can reflect scarce disease control and can negatively influence job performance. Due to the diagnosis and fear of ASM adverse reaction, PwE can experience a major mental strain in job performance and limited career choices [84].

Seizure type and severity influence the employability and job retention of PwE [4], [21], [23], [26], [27], [31], [39], [47], [48], [85]. In our population, seizure freedom ranged from 40% to 50% of respondents, though we cannot generalize these data. Cross-countries differences may reflect variations in clinical management, as well as different level of access to epilepsy care or higher fear of stigmatization/job demotion. Indeed, socially PwE tend to underreport seizures, fearing negative consequences in work environment [86].

Educational attainment and job positions in our sample varied widely, reflecting both the diversity of respondents and regional differences in schooling systems. Italy and Ireland showed higher proportions of respondents with high school diplomas, whereas in Bulgaria most participants have completed middle school.

Given the focus on employment, we compared unemployment rates among PwE with the general population in 2023. Although most PwE were employed in Italy and Bulgaria (70 and 95 respondents, respectively), the unemployment rate among Bulgarian PwE was twice that of the general population (9% vs. 4.5%), consistent with previous literature [17]. Salary distributions mirrored job positions: Bulgaria had the highest proportion of low-income respondents (n=184), possibly due to socioeconomic disparities, lower educational attainment, and higher levels of discrimination or institutional barriers.

Disclosure remains a complex matter for epilepsy. PwE often face a dilemma between early rejection when disclosing their condition and loss of trust or dismissal when not disclosing. Fear of accidental disclosure due to seizures at work may persist throughout an entire career. Though some advantages of disclosure are evident, PwE are not legally obliged to disclose their condition, except in specific circumstances (e.g., army). Recent studies proposed specific strategies to overcome disclosure limits and discrimination. Assertive impression management strategy can help PwE to get a better

position, during job interviews, overcoming limits perspective[87], [88]. An optimization of information flow between neurologists, occupational physicians and employers regarding seizures semiology, triggers, frequency and circadian distribution can ease the evaluation of applicant suitability for employers and employees [89]. In our survey, Italian PwE tend to disclose their condition, at least to employers. In Ireland, France and Germany most of the population disclosed their condition. Selective disclosure may serve as a protective strategy, even if it can lead to hardship in relationships with co-workers. In Bulgaria, nearly half did not disclose, likely because of fear of job loss, lower education, and higher perceived stigma.

Interestingly, most respondents reported no difficulties with colleagues or employers. This may reflect non-disclosure, absence of seizures at work, or, genuinely, more inclusive environments shaped by growing awareness of epilepsy and disability rights. Even in Reckin study in 2025, participants reported few cases of discrimination in school or at workplace [84]. We are witnessing a change in social awareness and general environment, tightly connected to impressive initiatives as “Out of the shadows”, a campaign promoted by the World Health Organization, the International League against Epilepsy, and the International Bureau for Epilepsy [90], [91].

In contrast, half of our population declared that PwE must face more challenges in workplaces and about two thirds of population accounted stigma as a crucial barrier for having and maintaining a good job. For PwE internalized stigma and discrimination still impair job quality and position, as well as advancement in employment. These findings align with previous evidence about the negative impact of stigma on social and work inclusion [9], [92].

Although statistical analysis was limited by sample heterogeneity and skipped questions, clear regional patterns emerged from our surveys. Bulgarian PwE showed a more fragile clinical profile: lower seizure freedom (89 SF vs 109 NSF), more frequent GTCs, lower education and income, higher perceived stigma and lower disclosure rates. On the opposite, other countries showed a profile characterized by intermediate levels of seizure freedom, medium-high educational levels, moderate stigma, and higher levels of disclosure. These findings reinforce the idea of increased

socioeconomic vulnerability for some specific countries, resulting in external barriers to work integration.

The HEI survey also showed cross-country differences. Most respondents correctly identified epilepsy as a neurological and treatable condition, except in Bulgaria, where 30% did not. This highlights persistent cultural and informational gaps. Consistent with earlier studies, misconceptions about safety and employability remain an invisible barrier for PwE [9], though accidents and absenteeism have been proven to be comparable to the general population [13], [14], [15].

While many HEI respondents knew someone with epilepsy, most were unfamiliar with basic first aid procedures for seizures, particularly in Bulgaria. This gap underlines the need for targeted education. Encouragingly, most HEI respondents did not believe PwE have higher absenteeism compared to the general population. These findings mirror the developing of better attitudes in hiring PwE among HEI. Even Hicks and Hicks (1956–1986) documented increasing willingness among major employers to knowingly hire PwE [93]. In the Czech Republic, public attitudes improved significantly between 1981 and 1997 [94], [95].

Finally, we have asked about economical support from institutions, and, except in Ireland and France, HEI reported receiving no financial incentives to employ PwE.

Overall, our findings emphasize the need to strengthen epilepsy knowledge among employers and HEI to foster inclusive workplaces, following exemplar models such as the Dutch “Horizon” program [64], [74], [96].

Yet, education alone is not sufficient, and, despite virtuous attempts by ILAE and IBE in work inclusion and disabilities rights, PwE still pay invisible costs as regards social and work integration.

Training programs for employers and a job application process guided by healthcare professionals are the key elements to break down stigmatization and increase social inclusion. To address this need, we have developed the two learning modules, confirming that epilepsy represents not only a neurological condition, but a social disorder [97]. Thus, government and administrations cannot ignore the necessity of

specific legislation to preserve PwE from discrimination. In this light, employment inclusion has become a matter of utmost importance internationally. WHO drafted the Intersectoral Global Action Plan (2022-2031) to overcome employment difficulties for people with neurological disorders, in particular epilepsy. The establishment of IGAP will lead countries to develop or update their legislation to promote and protect the human rights of PwE [98]. Also, IBE provided guidelines to employ PwE, avoiding blanket restrictions and promoting individual assessment, vocational programs, with the aim to fight discrimination and support equal opportunities [99].

### **Strengths and limitations**

Our review seems to be comprehensive and extensive, describing the unemployment situation in Europe over the last 60 years, including longitudinal studies about specific conditions. The wide extension of years and conditions considered make this review noteworthy, laying the background for future studies in social field.

We have focused on European literature since this review is a deliverable of the EpilepsyPOWER European Project Erasmus + (project 2021-1-IT02-KA220-ADU-000028349). Main limitations for the review were variability among reported rates of employment/unemployment, different sample dimensions, different time of observation (longitudinal vs transversal studies), and methodology of reported studies. Another limitation is the heterogeneity of population considered as employed (e.g., part-time) and unemployed (e.g., housewives). Some of the reviewed papers used surveys, so they could be affected by compilation biases. Finally, some other papers do not report the comparison with the general population.

Our surveys displayed results from a multicentric cross-sectional study. They illustrated from one side differences in clinical factors, socioeconomic variables, and barriers (stigma and challenges) for PwE, from the other side the knowledge of epilepsy and the support for companies for HEI. Main limitations were compilation, self-selection and non-respondent biases (“skipped” questions).

## **Conclusion**

Our review enlightens the difficulties faced everyday by PwE in workplaces. Although rates of unemployment are not uniformly reported, a clear situation of disadvantage rises for PwE in Europe. Reasons for unemployment range from seizure control to discriminatory employer's attitudes. Spreading awareness and knowledge about epilepsy among employers and caregivers could foster inclusion in workplaces, fighting stigma and ignorance. Providing PwE the right tools to choose the most suitable job and information about their disorder could help them to obtain the appropriate position. Having good seizure control could help PwE to get and retain a job, leading them to independence, better self-esteem, and social integration.

Both for PwE and HEI, social barriers, and stigmatization in some specific countries, especially in East Europe, prompts to underemployment and lower salaries. Our surveys confirm the need of spreading information about epilepsy for PwE, caregivers, colleagues, and employers, aiming to overthrow social stigmatization.

Final steps of our project were intended to increase the knowledge of epilepsy for PwE and HEI, looking forward to working on a specific legislation to protect and help PwE, allowing them safe access to workplaces.

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