

Epilepsy and Employment in Scotland

A scoping exercise for Epilepsy Scotland

Patricia Findlay¹, Johanna McQuarrie¹,

Emma Congreve²

¹Scottish Centre for Employment Research, University of Strathclyde, ²Fraser of Allander Institute, University of Strathclyde

Introduction

Epilepsy is one of the most common neurological conditions around the world, affecting an estimated 50 million people (WHO, 2019). Labour market data shows that people with epilepsy experience disadvantage in employment and underemployment. Inconsistencies and gaps in the data available on epilepsy and employment, however, make unclear the extent and scope of this disadvantage.

Employment is an important component of social inclusion. It provides individual purpose and a platform for membership and identity (Jahoda, 1982). It provides integration into and acceptance by others in society (Baker, 2005). Employment and good quality work are associated with wellbeing (Stanley and Tiltson in Jacoby, 1995). It is as important, and arguably more so (Ben et al, 2021) for people with epilepsy who are more likely than the labour force more generally to have experienced years of disadvantage in accessing this important component of quality of life (Smeets et al, 2007).

The purpose of this report is to review and update discussion of epilepsy and employment. The review seeks to identify relevant data and data gaps as well as to highlight the forms of support and intervention that can improve employment opportunities and work experience for people with epilepsy. It focuses on the extent of existing disadvantage they face and the factors that contribute to or alleviate this disadvantage. While the purpose of the review is to consider epilepsy and employment in Scotland, there are significant challenges in obtaining relevant Scottish data. Therefore, this report draws mainly on UK data but where possible focusses on implications for Scotland.

The review finds that there are significant and important gaps in data and in our understanding of the impact of epilepsy on employment and work. It highlights that there has been little improvement for decades in the quality of data in this area, and that despite the existence of protections against disability discrimination and the availability of policy and practice interventions that might support people with epilepsy in employment, there is little understanding of how interventions and support might and do work. The review concludes by considering how better

knowledge of epilepsy as a variable condition might shape interventions that can improve inclusion, and by highlighting how data limitations are harming the design, development and deployment of potentially positive interventions.

Epilepsy and the scale of the epilepsy employment gap

Epilepsy is described as ‘a condition that affects the brain and causes repeated seizures’, the severity of which differ from person to person. Seizures manifest differently with some people experiencing ‘an odd feeling with no loss of awareness’ while others might ‘lose consciousness and have convulsions’ (NHS 2021). The recovery time from a seizure can also differ accordingly depending on the type and severity of the seizure. In the UK, the number of people living with epilepsy is estimated at between 500,000 (NHS Inform, 2021) and 600,000 (IES, 2019; Epilepsy Research, 2021). In Scotland, it is estimated that 54,000 (1 in 97) people live with epilepsy (Joint Epilepsy Council, 2011). This is slightly higher than the figure reported in the last round of Scotland’s Quality and Outcomes Framework data (41,000 in 2013/14).

Epilepsy generally meets the definition of disability under the Equality Act 2010 (and previously under the Disability Discrimination Act 1995) and the condition is relevant when considering organisational policies that seek to better include people with a disability and protect them from discrimination.

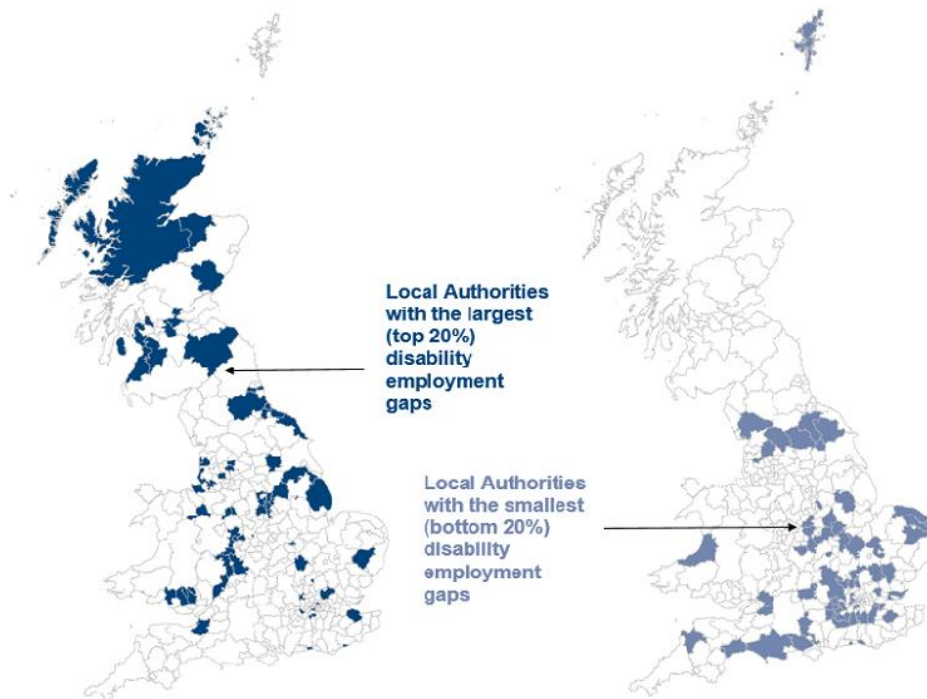
The Scottish Government seeks to enable citizens with disabilities to participate fully in paid employment, and in publishing *A Fairer Scotland for Disabled People* (2016) outline their ambition to reduce ‘by at least half, the employment gap between disabled people and the rest of the working age population’ by 2038. By the time of the 2018 update on progress towards *A Fairer Scotland for Disabled People Employment Action Plan*, the disability employment gap had fallen from 38.3% in 2015/16 to 35.3% in 2017/18, and the disability employment rate had increased from 41.7% in 2015/16 to 45.7% in 2017/18. While these gains have continued, the most recent figures have been captured during the first 18 months of the Covid-19 pandemic and as such should be treated with care (ONS, 2021).

	UK 2020/21	Scotland 2020/21
Disability employment gap	27.9%	32.8%
Disability employment rate	52.5%	47.4%

APS data for Scotland in 2020/21 showed a disability employment gap of 32.8% in March 2021, with the disability employment rate sitting at 47.4%. Comparable data for the UK shows a disability employment gap of 27.9%, and a disability employment rate of 52.5%. While there are strong geographic variations in the disability employment gap and rate across UK local authorities - with the former ranging from 8.4% in Harrogate to 50% in Na h-Eileanan Siar; and the disability employment rate ranging from 77.7% in Dartford to as low as 32.3% in Three Rivers – it is clear that local authorities with the largest and smallest disability employment gaps are

concentrated in particular parts of the UK, with Scotland featuring heavily in those local authorities with the largest employment gaps (APS data 2017 to 2019 period).

Figure 1: Disability employment gap (percentage points) by Local Authority, people aged 16 to 64, Great Britain, 2017 to 2019



Source: Annual Population Survey: The Employment of Disabled People, 2021.

Data from the APS highlights that the disability employment gap is wider for disabled men; older (aged 50 to 64) disabled people; disabled people with no qualifications; disabled people of White ethnicity; and disabled people living in Northern Ireland, Scotland, Wales, West Midlands, North West, and North East.

Disabled people are also more likely than non-disabled people to be working in lower-skilled occupations; self-employed; working part-time (and subsequently working fewer hours); and to be working in the public sector.

Turning specifically to people with epilepsy (PWE), their employment rate is only known at UK level.

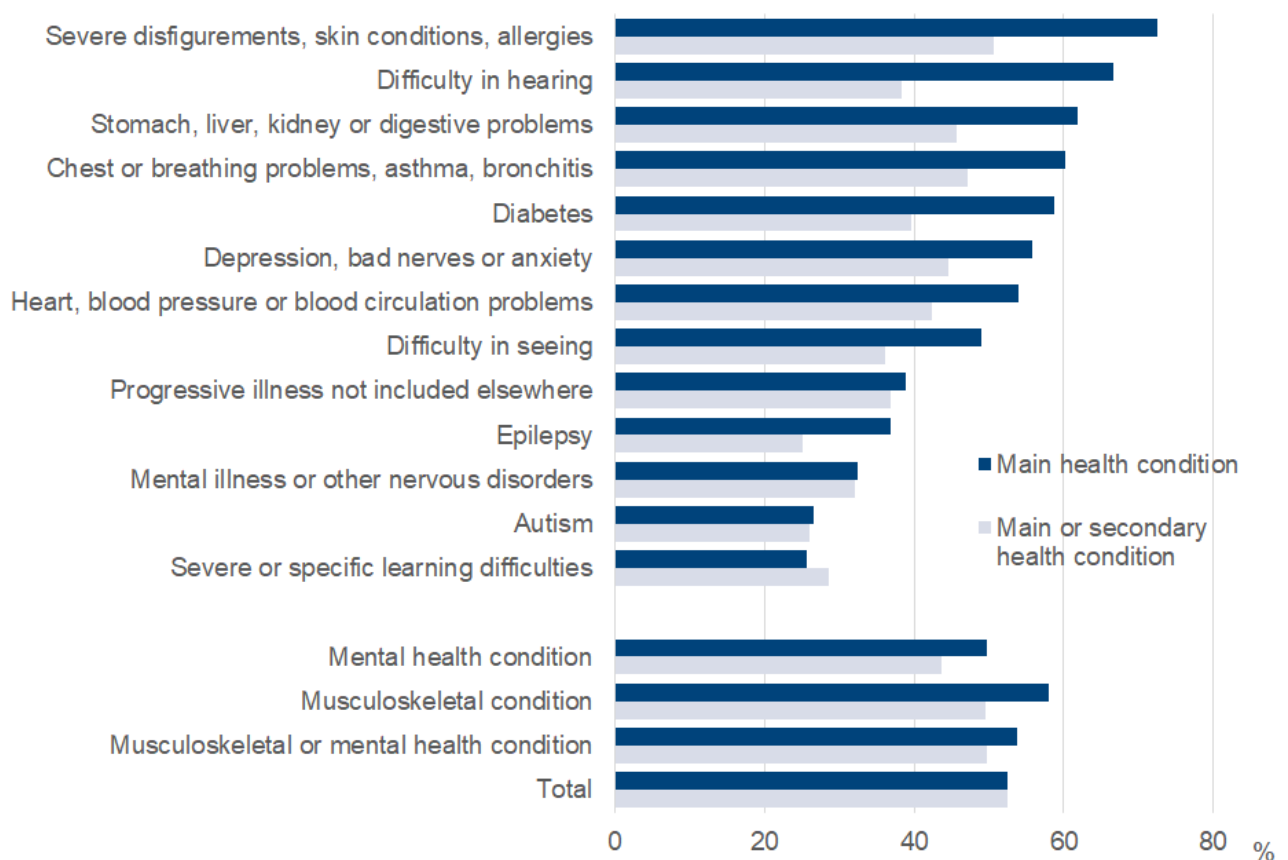
PWE in employment (APS 2020/21)	Non-disabled people in employment (LFS 2020)
36.9%	81.3%

The epilepsy employment gap for the UK in 2020 was higher than for the disability employment gap, with only 36.9% of PWE in the UK reported as being in employment in the Annual Population Survey (APS) (epilepsy reported as a main condition in the 2020/2021 period; ONS 2021). Relative to the 81.3% of non-disabled

people in employment (Labour Force Survey, 2020) there is a substantial employment gap of 44.4 percentage points for PWE. For PWE, employment is also less likely to be achieved than for all people with a disability. According to the Department for Work and Pensions (DWP), the disability employment gap in the UK is 27.4 percentage points with 53.6 of people with a disability in employment relative to 81% of non-disabled people (data drawn from APS and LFS Q2 2021, DWP, 2021). The figure from APS for the 2020-2021 period shows a slightly lower rate in employment (52.5%) increasing the gap to 28.5%. The disability employment gap has persisted around 30% for many years and while the years up to 2020 saw a small reduction in the gap (DWP, 2020), more recently small increases in the disability employment gap have been reported (TUC, 2021; DWP, 2021; ONS 2021).

While the problems of unemployment and underemployment are reported to be widespread among people with a disability, labour market data for the UK shows it to be a particular challenge for PWE. As shown in Fig.2 below, data from the Annual Population Survey for the UK (ONS, 2021) shows that PWE are one of the groups least likely to report employment relative to all people with a disability of any kind.

Figure 2: Proportion of disabled people in employment by main or secondary health condition, people aged 16 to 64, UK, 2020 to 2021



Source: Office for National Statistics – Annual Population Survey

The scale of the employment gap between PWE and the rest of the population has been the focus of many studies and such a disability employment gap is reported across the globe (Chan et al, 2021; Jennum et al, 2021; WHO, 2019). Notwithstanding some inconsistencies across countries related to different diagnostic measures for epilepsy, there is some consensus that the scale of the employment gap is higher in low to middle-income countries (Smeets et al, 2007).

Once in employment, PWE can also experience underemployment in terms of working time and relative to their skills and qualifications (Bishop and Chui, 2011; Jacoby, Gorry and Baker, 2005). The most recent quarterly report of the UK Labour Force Survey (April – June 2021) shows that 11% of PWE report being in employment but wanting more hours relative to 8% of the wider labour force who report underemployment. Smeets et al (2007) also note that PWE are more likely to be employed in low-skilled and manual occupations and that many are unable to fulfil their employment potential in aligning employment with their level of qualification. This is consistent with data on disability in general - as ONS (2021) has noted recently, a disabled person with A levels is as likely to be in employment as a non-disabled person with no qualifications. Disability, including epilepsy, not only impacts attaining employment, it may also be related to a greater likelihood of losing employment. APS data has recently shown that people with a disability are more likely than others to work in occupations and sectors that closed during the COVID-19 pandemic, increasing the risk of redundancy and underemployment (Blundell et al, 2021; National Disability Strategy, 2021).

The challenge for PWE in obtaining and maintaining employment is longstanding, with experiences of disadvantage widely rehearsed in existing literature (Swartz and Dennerll, 1967; Jacoby, 1995; Smeets et al, 2007). The ongoing nature, experience and persistence of disadvantage facing PWE is particularly frustrating given improvements in clinical interventions and the enactment of legislation to make disability discrimination unlawful and to support equality of opportunity (Bishop and Chiu, 2011).

What drives the ‘burden of epilepsy’?

There is considerable consensus in more recent literature that the drivers of employment and other disadvantage for PWE are multifactorial and interacting (Smeets et al, 2007; Bishop and Chiu, 2011; Baker, 2017). In a systematic review of the literature on the drivers of disadvantage for PWE, Wo et al (2015) find clinical, educational, political and psychological factors are important:

- Clinical factors are identified as presenting barriers to employment particularly where seizures are not controlled.
- Educational factors can present barriers where PWE carry disadvantage from the education system to the labour market (Chan et al, 2021). PWE may struggle with school attendance due to the nature of their condition, and uncontrolled seizures, including absence seizures, may detract from their learning opportunities while in school. Either scenario can lead to a lower level of education and qualification than might otherwise have been achieved.

- Political factors can be a source of disadvantage in terms of restricting access to some occupations (e.g. the armed forces) and placing some restriction around obtaining/maintaining a driving license.
- Psychological factors include experience of and internalising of stereotyping and stigma (Chan et al, 2021; Kimiskidis, 2007 in IES). Research has highlighted that reports of low self-esteem & self-efficacy are common in PWE. Internalised stigma and expectations of rejection (Smeets et al, 2007) are related to institutional and interpersonal stigma that triggers discriminatory reactions (Jacoby and Austin, 2007).

Medical models of disability focus heavily on the individual and the impairment as the driver of disadvantage experienced by PWE, yet Wo et al (2015) argue that many clinical drivers of disadvantage can be addressed through treatment and medication, thereby reducing the extent to which the condition itself should be seen as the primary driver of disadvantage. These authors find evidence across the existing literature that non-clinical factors such as discrimination and stigma are dominant.

Social models of disability focus more on the barriers to employment that exist because of the attitudes and perceptions of disability held by people and society. The disability (as distinct from the impairment) is seen as socially constructed. Social factors driving employment disadvantage for PWE include a wariness among employers and co-workers about working alongside a person with epilepsy (YouGov 2016 in IES, 2019; Holmes, Bourke & Plumpton, 2019). Employers report that their concerns focus primarily on safety issues arising from the possibility of seizures in the workplace, particularly in relation to jobs that involve machinery, driving, working alone or caring for others (IES, 2019). In their survey of the stigma of epilepsy, Holmes, Bourke & Plumpton (2019) find similar attitudes within a sample of the general population in the UK. While this group did not support some negative stereotyping around PWE, perceptions of what is safe in terms of operating machinery, driving and caring were of most concern. Yet there is little evidence to support the view that people with epilepsy who are in employment experience more workplace accidents than those without the condition (Johnson, 2016).

While employer attitudes on employees with epilepsy in the UK are shown to have improved, there remains considerable room for further improvement (Jacoby, Gorry and Baker (2005). Poor awareness of the condition is often associated with misconceptions around the abilities PWE have and what occupations they can do, much of which treats PWE and their condition as homogeneous, ensuring that all PWE are perceived in terms perhaps only applicable to some and possibly only a minority. This might mean, for example, that employers limit the possible activities of PWE more than their individual experience of their condition requires, for example, precluding them from working alone when there is no reason to. More positively, however, there is some evidence that employers are more willing to make adjustments to work if the person is an existing employee (IES, 2019) which suggests that once they have exposure to epilepsy in the workplace, PWE are perceived as bringing less risk to the workplace and the employer.

Yet prevailing myths, stereotyping and stigma associated with epilepsy may deter PWE from disclosing their condition (Swartz and Dennerll, 1967), particularly where

it is well-controlled (Smeets et al, 2007). This has two important implications. First, it may mean that data on epilepsy and employment is less accurate and that more PWE may well be in employment and also performing those jobs that are widely perceived as high risk for those with the condition. Second, it may mean that PWE are less likely to be able to access reasonable adjustments at work. Each of these implications are looked at in turn below.

Jacoby (1995) collected employment data from 494 participants in an antiepileptic drug study, recruited from outpatient departments. All participants had their epilepsy under control with many having been seizure-free for some time. In this sample, 71% were in employment, 26% were not but cited reasons other than epilepsy, and 3% cited epilepsy as the cause for their unemployment. It is therefore possible that the number of PWE active in workplaces at present is higher than reported in national statistics, although significantly lower employment rates may accurately reflect those PWE with the most frequent and disruptive seizures (Smeets et al, 2007).

It is also possible that PWE who do not disclose their epilepsy experience disadvantage as they do not request reasonable adjustments to their condition and hence face a 'burden of normality' arising from the invisibility of their condition alongside the 'burden of epilepsy' arising from the condition itself. This may generate more negative outcomes for work experience and career development.

A key challenge in addressing employment disadvantage faced by PWE is the lack of both broader and deeper data on how living with epilepsy impacts employment and work. As Jacoby and Austin (2007) argue, the 'remnants of old ideas' continue to generate 'social and quality of life problems ... [that] ... represent greater challenges than are warranted by its clinical severity' for PWE. If *A Fairer Scotland for Disabled People* is to be achieved, it is important to deconstruct epilepsy as the 'master status' that overrides the character of an individual and assigns a 'spoiled identity' (Goffman, 1963 in Smeets et al, 2007) that can have material consequences for PWE. At present, there is little data that allows for a more nuanced understanding of the relationship between individual experience of epilepsy and employment.

Barriers to greater understanding and insight

Problems with the evidence base around epilepsy, employment and work are often raised in the literature. Jacoby (1995) highlights concern with the extent to which many studies use small samples and/or highly selected populations. As most studies focus on PWE recruited through support organisations or specialist clinics, the studies tend to reflect those for whom epilepsy has the greatest impact on their lives, which Jacoby (*ibid*) argues is only a third of the population of PWE. As her own research illustrates, the employment experiences of people with well-controlled epilepsy may be distinctly different from those with poorly controlled epilepsy.

There is no 'one size fits all' in how epilepsy manifests yet too often epilepsy is seen as an all-encompassing condition in which everyone diagnosed with the condition experiences the same type of seizure, most notably tonic-clonic seizures whereby the persons loses consciousness and convulses. It has long been acknowledged in

the literature that epilepsy is a condition that is often misunderstood in terms of its manifestations, severity and treatment (see Swartz and Dennerll, 1967).

There are different types of seizure that manifest different symptoms, and which differ in terms of severity and recovery. While some seizures are antecedents for others that are more severe, for many PWE the less severe manifestation represents the extent of their condition and in some cases can be outgrown. For others, up to 70% are capable of full seizure control (WHO, 2019) to the extent that many PWE can live seizure-free (Bell & Sander, 2001; Goodridge and Shorvon, 1983). Employment data, however, only captures whether someone has or has had epilepsy rather than the extent to which it impacts their daily lives.

Data sources on employment in the UK mostly comes from sample surveys. These surveys allow for interviewers to ask additional questions alongside labour market information. Most sample surveys that include questions on employment also ask about disability and/or ill health.

All surveys usually have similar questions to determine whether or not a participant meets the eligibility to be considered as disabled under the Equality Act 2010. In line with the statutory definition of disability, this means that the participant has a “physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities”ⁱ.

Beyond this, however, survey questions on types of disability and long-term ill health differ substantially. We have reviewed the major sample surveys on employment to look at a) whether respondents are asked about epilepsy b) the reliability of the data depending on sample size.

[Labour Force Survey and Annual Population Survey – Office for National Statistics](#)

The labour force survey contains a breakdown of main health issues, including epilepsy.

Do you have...

- 1 problems or disabilities (including arthritis or rheumatism) connected with your arms or hands?
- 2 ...legs or feet?
- 3 ...back or neck?
- 4 difficulty in seeing (while wearing spectacles or contact lenses)?
- 5 difficulty in hearing?
- 6 a speech impediment?
- 7 severe disfigurements, skin conditions, allergies?
- 8 chest or breathing problems, asthma, bronchitis?
- 9 heart, blood pressure or blood circulation problems?
- 10 stomach, liver, kidney or digestive problems?
- 11 Diabetes?
- 12 depression, bad nerves or anxiety?
- 13 Epilepsy?
- 14 severe or specific learning difficulties?
- 15 mental illness or suffer from phobias, panics or other nervous disorders?

16 progressive illness not included elsewhere (eg cancer not included elsewhere, multiple sclerosis, symptomatic HIV, Parkinson's disease, Muscular Dystrophy
 18 Autism (including autism spectrum condition, Asperger syndrome)
 17 other health problems or disabilities?

At the UK level, 264 people in the sample reported epilepsy as their main health condition in Q2 2021 (ONS LFS April), which when weighted to the population equates to 208,512 or roughly 0.3% of the UK population. This figure differs substantially from other quantifications of the population with epilepsy reported (500,000 – NHS; 600,000 – IES, 2019).

Table 1: Respondents in April – June 2021 LFS sample who report epilepsy as their main health condition

	In employment	Unemployed	Inactive	Total
UK	135	13	116	264
Scotland	14	1	8	23

Source: LFS Apr-June 2021, HEALTH20

The Scottish LFS sample is far too small to use reliably. For Scottish labour market analysis, the Annual Population Survey (APS) dataset is usually used. The APS uses data combined from 2 waves of the LFS with a local sample boost. At present, however, there is no published breakdown of the APS numbers for people in Scotland with epilepsy.

Family Resources Survey – DWP

The Family Resources Survey is the main source of data on incomes and it contains some information on employment, as well as a breakdown of long-term health conditions and disabilities. However, the information provided on health conditions is at a high level, and it is not possible to identify those who have epilepsy from the data.

Do any of these conditions or illnesses affect you in any of the following areas?

1. Vision (for example blindness or partial sight)
2. Hearing (for example deafness or partial hearing)
3. Mobility (for example walking short distances or climbing stairs)
4. Dexterity (for example lifting and carrying objects, using a keyboard)
5. Learning or understanding or concentrating
6. Memory
7. Mental Health
8. Stamina or breathing or fatigue

Growing up in Scotland – Scottish Government

Growing up in Scotland is a longitudinal survey that looks at various aspects of child and family life. Questions on epilepsy are asked in the survey, but unfortunately only in relation to the child, and hence are not readily connected to employment experience.

Understanding Society – University of Essex

Understanding Society is a UK-wide longitudinal survey and includes a question on whether respondents have (or have ever had) epilepsy. The survey also includes question on work status and other variables, including income. The survey can be used for cross-sectional and longitudinal analysis.

1. Asthma
2. Arthritis
3. Congestive heart failure
4. Coronary heart disease
5. Angina
6. Heart attack or myocardial infarction
7. Stroke
8. Emphysema
9. Chronic bronchitis
10. COPD
11. Hypothyroidism or an under-active thyroid
12. Any kind of liver condition
13. Cancer of malignancy
14. Diabetes
15. Epilepsy
16. High blood pressure/hypertension
17. An emotional, nervous or psychiatric problem
18. Multiple Sclerosis
19. H.I.V
20. Other long standing/chronic condition
21. None of these

Looking at the most recent wave of data at the UK level, the sample of individuals that mention epilepsy is 306. The Scottish sample only includes 25 recipients. This sample is therefore too small to breakdown and use to analyse employment status.

Overall, the lack of detail and adequate sample size for analysing national data makes it challenging to fully understand the relationship between levels of seizure control in epilepsy and employment.

There are some glimmers of hope in accessing better data on epilepsy and employment, though these are some years from fruition. Given the absolute numbers of number of people with epilepsy in Scotland, detailed analysis on employment could be served by using linked administrative data records. While relevant administrative data is not currently available, initiatives such as Research Data Scotland aimed at improving capabilities in Scotlandⁱⁱ may in time allow for the linking of employment and benefit data and health data. Employment and benefit data includes HMRC data on income and DWP data on benefits such as Universal Credit, alongside data held by Social Security Scotland on additional cost disability benefits. Accessing this data for data linkage is currently incredibly difficult, although Research Data Scotland are working with the UK Government and Social Security

Scotland to try to improve capabilities in future, which would capture information on those claiming benefits (though would exclude those who don't).

A range of data is also collected by health and social care services, and some of this data is available for research purposes. Some data, such as prescription data, is known to be of sufficiently good quality for research purposes although is not linked to other data on employment status, occupation, and/or level of qualification. Other data, such as from GP records, is not yet sufficiently consistent and complete for robust research. Improvements in this area may accelerate in the next few years, spurred on by digital improvements made during the pandemicⁱⁱⁱ. In the long run, this may be the only means of accessing data that is sufficiently sensitive to variations in epilepsy symptoms, seizure control and treatment to allow for meaningful quantitative analysis on the relationship between epilepsy and employment and, crucially, to underpin forms of support and intervention that are sensitive to individual need and that can improve the employment experience of PWE.

Underpinning the strategic framework for a *Fairer Scotland for Disabled People* is the realisation that 'progress [to reducing the UK disability employment gap] has been too slow and it's time to be more proactive'. It is further noted that it could take 200 years to halve the gap at UK level which Scotland aims to achieve by 2038. Without the data to understand the nature and scope of the challenge, it is difficult to see how PWE will be included in and benefit from this ambition.

Which way forward?

As Smeets et al (2007) noted in their systematic literature review, the impact of epilepsy and seizures on employment is under-researched, and the long-standing debates on epilepsy-related disadvantage continue. In relation to employment, the challenge is clear: to both explain and address the very low proportions of PWE in employment in ways that drive the design of solutions, impact and progress.

The typologies of epilepsy have long been lost in an overarching categorisation that does not enhance understanding and arguably increases stigma. Public perceptions, organisational practice and policy continue to be influenced by a dominant – and potentially inaccurate – depiction of the experience of living with epilepsy. A more nuanced understanding of epilepsy as a complex and variable condition is needed to drive better insight into the relationship between epilepsy, work and employment. While analysis of the lived experience of PWE is crucially important in this regard, so too is data that can identify patterns and variation. Data must, however, be sensitive to the variations in the condition, and to seizure control in particular, and how this shapes employment experience and outcomes.

While the developments around linked administrative data in Scotland is encouraging, the same debates and disadvantage continue during those years of waiting and the 2038 target in Scotland to halve the disability employment gap gets closer.

Developing effective policy and practice requires reliable data and evidence. To support progress towards a *Fairer Scotland*, there is a clear and as yet unmet agenda for people with epilepsy. This agenda might usefully focus on the following questions:

- At national level, how reliable are current UK statistics in relation to the participation of PWE in employment, and what does this mean for PWE in Scotland?
- At regional level, does the pattern of geographic variation in the disability employment gap and rate hold for PWE, and how does this look in the specific context of Scotland? What role does industry/sectoral composition at a regional and local authority level play in the employment gap and outcomes for disabled people, and PWE in particular? What role does the state of the labour market play in shaping the employment outcomes for PWE? How might better understanding of these issues shape policy on economic development and business support?
- At organisational level, how can understanding of the employment potential for PWE be enhanced? What organisational factors shape employer responses to the employment and work of PWE? What are the organisational examples of good practice in supporting PWE, including in disclosure of their condition and the provision of relevant adjustments where required? How can these be used to support effective business to business, organisation to organisation learning?
- At occupational and individual level, what is the impact of epilepsy not just on accessing employment, but on the quality of that employment and the sustainability of employment and labour market participation? What individual and organisational factors shape the willingness of PWE to disclose their condition to employers? What are the consequences of disclosure or non-disclosure of epilepsy? What are the types of adjustments requested and/or made available by employers to people with epilepsy? What are the consequences in terms of the 'burden of normality' for PWE who choose not to disclose their condition?
- At policy level, what are the approaches, targets and measures that can drive measurable change? What is the role of supported employment? While longitudinal data of vocational rehabilitation programmes is scarce (Smeets et al, 2007), what is the role and impact of supporting interventions specific to epilepsy?

This review has summarised existing knowledge on the relationship between epilepsy and employment while also highlighting important gaps in our current knowledge and understanding. The significant under-representation of PWE epilepsy highlights the consequences of these knowledge gaps. Put simply, there are strong

reasons to believe that better knowledge and understanding could be transformative for PWE and their experience of the world of work.

This review suggests a bold agenda for policy-makers, employers, campaigning organisations and other relevant stakeholders such as trade unions and researchers, an agenda that grasps the nettle of why PWE fare so poorly in employment and commits to practical actions aimed at changing that experience. This agenda is necessarily collaborative and existing campaigning channels and relationships will be crucial to supporting the design and development of effective collaboration.

It is difficult, however, to see how the paucity of data outlined above can be addressed in the short to medium term without dedicated research investment. Any such investment holds the prospect of potential returns that go far beyond a simple advance of knowledge: better data and understanding can help define the particular challenges facing PWE in employment, design interventions at policy and organisational level that can address these challenges, support and encourage employers to engage with the specific needs of PWE and in so doing harness the talents and efforts of a significantly under-utilised group of workers, while also improving the quality of working life and by association the quality of life for PWE. Attention to delivering these mutually beneficial outcomes is long overdue.

References

World Health Organisation (2019), *Epilepsy, A Public Health Imperative*, Geneva: World Health Organization; 2019. Licence: CC BY-NC-SA 3.0 IGO.

Baker GA. Employment. In: Sander JW, Walker MC, Smalls JE, editors. *EPILEPSY 2005 from neuron to nice: a practical guide to epilepsy: lecture notes*. St. Anne's College, Oxford: ILEA; 2005. p.495–9.

Baker G A (2017), 'Employment', in Rugg-Gunn F J and Stapley H B [EDS] *From Bench to Bedside: A Practical Guide to Epilepsy*, Epilepsy 2017 London: International League Against Epilepsy pp. 547-554.

Bell, G.S., and Sander, J.W. (2001), CPD — Education and self-assessment The epidemiology of epilepsy: the size of the problem, *Seizure*, Volume 10, Issue 4, pp 306-316, <https://doi.org/10.1053/seiz.2001.0584>.

Ben, J., Pagani, A.G. Souza Marques, B. Fialho, G.L., Wolf, P., Walz, R., and Lin, K. (2021), Employment status as a major determinant for lower physical activity of patients with epilepsy: A case-control study, *Epilepsy & Behavior*, Volume 115.

Bishop, M., & Chiu, C.-Y. (2011). Epilepsy and employment. In J. Pinikahana & C. Walker (Eds.), *Society, behaviour and epilepsy* (pp. 93–114). Nova Biomedical Books. Chan, M.H.H., Leung, W.C.Y., Lou, W.Q.V, Lo, C.N.R., Chang, R.S. (2021) Employment among people with epilepsy in Hong Kong, *Epilepsy & Behavior*, Volume 124.

Blundell, R., Joyce, R., Costa Dias, M. and Xu, X. (2020), *COVID-19: the impacts of the pandemic on inequality*, Institute for Fiscal Studies. Social Metrics Commission (2020), *Poverty and COVID-19*.

DWP (2020), *The Employment of Disabled People*, Available: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/875199/employment-of-disabled-people-2019.pdf [Accessed October 2021]

DWP 2021, *The Employment of Disabled People 2021*, Available: <https://www.gov.uk/government/statistics/the-employment-of-disabled-people-2021/the-employment-of-disabled-people-2021>, [Accessed October 2021]

Epilepsy Research (2021), *About Epilepsy* (webpage), Available: <https://epilepsyresearch.org.uk/about-epilepsy/> [Accessed: October 2021]

Fisher RS. Epilepsy from the patient's perspective: review of results of a community-based survey. *Epilepsy Behav* 2000;1:S9–S14

Goodridge, D.M. and Shorvon, S.D. (1983) Epileptic seizures in a population of 6000. I: Demography, diagnosis and classification, and role of the hospital services. *Br Med J (Clin Res Ed)* 1983; 287 doi: <https://doi.org/10.1136/bmj.287.6393.641>.

Holmes, E., Bourke, S., & Plumpton, C. (2019), Attitudes towards epilepsy in the UK population: Results from a 2018 national survey, *Seizure*, Volume 65, Pages 12-19.

HM Government (2021), *National Disability Strategy*, Crown: UK.

Institute for Employment Studies (IES), (May 2019), Employment support for people with epilepsy, Report 523. Available: <https://www.employment-studies.co.uk/system/files/resources/files/523.pdf> [Accessed May 2021]

Jacoby, A., Gorry, J. and Baker, G.A. (2005), Employers' Attitudes to Employment of People with Epilepsy: Still the Same Old Story?. *Epilepsia*, 46: 1978-1987. <https://doi.org/10.1111/j.1528-1167.2005.00345.x>

Jacoby, A. (1995), Impact of epilepsy on employment status: Findings from a UK study of people with well-controlled epilepsy, *Epilepsy Research*, Volume 21, Issue 2, pp 125-132. [https://doi.org/10.1016/0920-1211\(95\)00013-Z](https://doi.org/10.1016/0920-1211(95)00013-Z).

Jacoby, A. and Austin, J.K. (2007), Social stigma for adults and children with epilepsy. *Epilepsia*, 48: 6-9. <https://doi.org/10.1111/j.1528-1167.2007.01391.x>

Jahoda M. *Employment and unemployment: a social psychological analysis*. Cambridge: Cambridge Univ. Press; 1982

Jennum, P., Debes, N.M.M., Ibsen, R., Kjellberg, J. (2021) Long-term employment, education, and healthcare costs of childhood and adolescent onset of epilepsy, *Epilepsy & Behavior*, Volume 114, Part A.

Johnson, E. (2016), 'Perspectives on Work for People with Epilepsy', in *Handbook of Return to Work*, I.Z., Schultz and R.J. Gatchel (eds), Springer: New York.

Joint Epilepsy Council (2011), *Epilepsy prevalence, incidence and other statistics*, Available:

https://d3imrogdy81qei.cloudfront.net/instructor_docs/373/29_05_2016_Joint_Epilepsy_Council_Prevalence_and_Incidence_September_11.pdf [Accessed January 2022]

ONS 2021 Outcomes for disabled people in the UK: 2020, Available:

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2020#employment> [Accessed September 2021]

NHS (2021), NHS Inform: Epilepsy (webpage). Available:

<https://www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/epilepsy> [Accessed 01 November 2021]

Scottish Government, *A Fairer Scotland for Disabled People*, Available:

<https://www.gov.scot/publications/fairer-scotland-disabled-people-delivery-plan-2021-united-nations-convention/pages/3/> [Access November 2021]

Smeets et al. / *Epilepsy & Behavior* 10 (2007) 354–362

Schwartz, Melvin L; Dennerll, Raymond D. *Journal of Rehabilitation*; Washington, D.C. Vol. 33, Iss. 1, (Jan 1, 1967): 36.

TUC (2021), *Disability pay and employment gaps 2020*, Available:

<https://www.tuc.org.uk/research-analysis/reports/disability-pay-and-employment-gaps-2020> [Accessed November 2021]

Wo M C M, Lima K S, Choo W S, Tan C T (2015), 'Employability in people with epilepsy: A systematic review', *Epilepsy Research*, Vol. 116

YouGov (2016), Epilepsy in the workplace.

ⁱ <https://www.gov.uk/definition-of-disability-under-equality-act-2010>

ⁱⁱ <https://www.researchdata.scot/>

ⁱⁱⁱ <https://www.gov.scot/publications/scotlands-digital-health-care-strategy/pages/2/>