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Evidence-based profile of alcohol related brain damage in Wales

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Date: 1st March 2015

Version: 1c

Purpose and Summary of Document:

This document has been produced as part of the Programme Level Agreement (Substance Misuse Research and Analytical Support and Substance Misuse Treatment Framework Programme) between Welsh Government and Public Health Wales. The document provides an evidence-based profile on the scale of, and services in place for, individuals with alcohol related brain damage in Wales and recommendations for further action.

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Glossary

ARBD: Alcohol related brain damage, a spectrum of conditions characterised by cognitive impairment linked to excessive alcohol consumption

ARBI: Alcohol related brain injury: an alternative term for ARBD preferred in some countries, notably Australia

WKS: Wernicke-Korsakoff's syndrome

KP: Korsakoff's psychosis

KS: Korsakoff's syndrome

WE: Wernicke's encephalopathy

1 Executive Summary

- Alcohol Related Brain Damage (ARBD) is a term used to describe a spectrum of conditions characterised by prolonged problems with memory, reasoning and the processing of new information due to excessive alcohol consumption
- ARBD is not a degenerative condition, and up to 75% of patients will recover to some degree with abstinence and appropriate rehabilitative support
- ARBD encompasses a continuum from very mild to extremely severe
- ARBD patients are typically male, socially isolated, living in deprived areas and 50 to 60 years old, although younger patients are increasingly being identified. Women typically develop ARBD at an earlier age than men
- A conservative analysis of hospital admissions suggests that 241 Welsh residents (7.8 per 100,000) were diagnosed with ARBD in hospital in 2012, an increase of 38.5 per cent from 2008
- Evidence suggests that injectable thiamine may be underprescribed in Primary Care in relation to the number of patients who would benefit
- Evidence suggests that services need the capacity to retain some patients in the specialist residential settings for two to three years
- Existing services often fail to meet the needs of ARBD patients
- There is evidence that ARBD is increasing in the UK

2 Alcohol related brain damage (ARBD): an overview

2.1 What is ARBD?

Alcohol Related Brain Damage (ARBD) is a term used to describe a spectrum of conditions characterised by prolonged cognitive impairment due to changes in the structure and function of the brain linked to chronic, excessive alcohol consumption.^{1,2}

Brain damage in those who are alcohol dependent (i.e. will experience physical withdrawal without alcohol) has historically been considered to be relatively simple to explain in clinical terms, with patients believed to have developed 'alcoholic dementia', a condition of uncertain origin causing widespread cognitive dysfunction.³ Most of those experiencing alcohol-related cognitive problems were assumed to be experiencing one of a number of interlinked conditions: Wernicke's encephalopathy (WE), Korsakoff's syndrome (KS, also known as Korsakoff's psychosis, KP) and Wernicke-Korsakoff's syndrome (WKS, the presence of both WE and KS). These conditions are caused by a lack of thiamine (also known as vitamin B1) which is essential to maintaining the integrity of the nervous system.⁴ Although widely available in a range of foods and only required in small amounts, the body can only store a 4-6 week supply of thiamine.⁵ Heavy alcohol consumption depletes the body's stores of thiamine. An inadequate diet, which is often a feature of the lifestyle of those who are alcohol dependent, means these stores are not replaced.⁵ Alcohol also interferes with absorption by the body even when the diet contains thiamine.⁵

More recently, developments such as brain scanning technologies have demonstrated that the effects of heavy alcohol consumption on the brain in the long-term are considerably more complex than the simple clinical categorisation suggested previously.⁶ A better understanding of these complexities has led to the increasing use of 'alcohol related brain damage' (ARBD) as a term encompassing brain damage manifesting itself in different ways and at different points in the lifespan⁶ through multiple underlying mechanisms which are not yet fully understood.^{7,8} However, in the literature, terms such as 'alcoholic dementia', 'Korsakoff's syndrome' and 'alcohol-related brain damage' continue to be used interchangeably.⁹

ARBD refers to a wide range of specific disorders, including cerebellar atrophy, peripheral neuropathy, hepatic encephalopathy, and frontal lobe dysfunction, as well as WE, KS and WKS and comparatively rare conditions such as Marchiafava-Bignami disease and pellagrous encephalopathy.² The variety of conditions and wide individual variations in alcohol consumption and other lifestyle factors

means that ARBD symptoms exists across a lengthy continuum from very mild to extremely severe.¹⁰

2.2 Symptoms and diagnosis

There are currently no validated diagnostic criteria for ARBD, although validated criteria for 'alcohol related dementia'¹¹ have been adapted by one service to identify those with ARBD.¹² Three broad categories of signs and symptoms have been proposed to help identify those with ARBD:

1. Problems with long and short term memory, with 20 minutes suggested as a guide to amount of time specific information can be retained
2. Reasoning problems interfering with tasks such as weighing up options, understanding the implications of decisions and learning new information
3. Problems with impulse control, including difficulty managing emotions and aggression, tendencies to disclose personal information inappropriately times and difficulty in coping with even minor stressors¹²

Whilst many conditions that fall within the definition of ARBD do have clear diagnostic criteria, the presence of multiple and overlapping conditions may reduce the visibility of ARBD and ARBD patients within health and social care systems: for example, more than 40 different wordings were found to have been used by doctors on medical certificates provided in relation to patients with ARBD in one location.¹³

Multiple issues around presentation to clinical services and diagnosis can lead to cases being missed or undiagnosed¹⁴ including:

- The requirement for a period of abstinence prior to diagnosis¹¹
- Lack of appropriate guidelines and training (or guidelines not put into practice) across services including psychiatric inpatient wards,¹⁵ GP practices¹⁶ and Accident and Emergency Departments^{17,18,19}
- Overlap with non-alcohol related conditions such as other dementias²⁰
- Variable or incomplete clinical signs, notably with WE²¹
- The broad spectrum of damage associated with ARBD¹⁰
- The possibility that standard brief cognitive assessment tools may miss less severe damage.¹¹

Underdiagnosis of ARBD is an acknowledged issue not only within clinical settings but also in the community.²² Failure to present at services for reasons including stigma, is common.^{7, 14} It has been suggested that patients with WKS and related conditions usually first become visible to services when they are assessed at home or in general hospital settings and rarely through direct referral to psychiatric services, where their needs might be more quickly identified.²³ Issues of diagnosis in services are addressed in the recommendations.

2.3 Recovery and rehabilitation

Despite including a diverse range of conditions, ARBD has proven a useful way to define a category of patients with common social and clinical needs and similar prospects for rehabilitation.¹⁴ In particular, although at diagnosis those with ARBD typically need high levels of clinical and social care, ARBD is not a degenerative condition if the patient stops drinking.²³ It has been estimated that up to 75% can recover with appropriate rehabilitative support.⁸ When patients with ARBD are categorised by diagnoses or clinical coding, the range of different conditions within the ARBD spectrum means the need for, and value of, rehabilitative services specific to this group as a whole are not always clear. Many are referred to existing services, particularly those designed for older patients with dementia, where they often struggle to engage and settle, and where appropriate recovery-orientated care is not available.^{7, 8, 24}

3 ARBD in Wales: prevalence and epidemiology

3.1 Who suffers from ARBD?

Estimating the number and characteristics of people with ARBD is challenging. The evidence suggests that in general ARBD patients are typically in the age range 50-60 and male.^{1,2} This means that ARBD often affects individuals at a younger age than other cognitive conditions – such as non-alcohol related dementia – that require comparable levels of intervention.

Recent evidence relating to the profile of those with ARBD includes:

- Data from specialist services reporting mean ages of 54, 73% male and 55, 74% male respectively amongst referrals^{12, 25}
- A hospital-based study of 14 patients with WKS reported that seven were under 50, six were between 50 and 60 and none were over 65²⁶
- A review of 108 people with ARBD in Glasgow care homes found mean age at admission was 54 (80% male), but almost half the women admitted were under 50; the youngest person admitted was 31, and increasing numbers of younger referrals were reported²⁷
- KS admissions to a Glasgow hospital had a mean age of 56 for men and 50 for women, with a male:female ratio of 3:2; the duration of 'alcohol abuse' reported was 20 years for men and 16 years for women²⁸
- Scottish hospital discharge data suggests numbers of those diagnosed with ARBD are rising, with particular increases amongst men aged 40-60 and amongst those from more affluent areas.²⁹

However, the typical profile of an ARBD patient may conceal substantial differences between genders and increasing numbers of younger patients as the evidence relating to ARBD and the length of drinking careers in men and women dates back to the 1970s.³⁰ Variation in ARBD data by gender in more recent studies suggests further research is needed in this area.

Social isolation is a persistent theme amongst ARBD populations^{11,26} with a trajectory in which challenging life events precipitate increased drinking, leading to family and social network breakdown frequently reported.³¹ ARBD rates may be higher in socially deprived areas^{2, 32} although little evidence exists for causal links between deprivation and ARBD.

3.2 Lifetime prevalence

A number of studies have reviewed post mortems to establish lifetime prevalence rates of conditions related to ARBD. These studies have suggested a range of lifetime prevalence rates across the population for ARBD or related conditions:

- Lifetime prevalence of WKS between 0.1 per cent and 1 per cent across the population, with a UK rate of 0.5 per cent.³³
- Lifetime prevalence of WE of 1.5 per cent, but with rates varying from 0.4 per cent (France) to 2.8 per cent (Australia).³⁴
- Two Australian studies put the rate of WKS at 2.1 per cent³⁵ and 1.1 per cent;³⁶ the difference may be due to the decision in 1991 to fortify bread in Australia with thiamine, as it has been in the UK for over fifty years.³⁶
- Lifetime prevalence in Sweden of 0.8 per cent for WE and 1.7 per cent for alcoholic cerebellar atrophy.³⁷

It is also worth noting that international estimates of prevalence of WE and KS show no direct correlation with per capita consumption of alcohol.⁹

If the lifetime prevalence rates for WKS/WE indicated in these studies were generalised to Wales, they would suggest that between 15,000 and 84,000 Welsh people (0.5% and 2.8% of population respectively) would develop ARBD at some point in their lifetime. This wide range illustrates how challenging it is, with the current available evidence, to accurately estimate lifetime prevalence of ARBD.

3.3 Current prevalence

Estimates of the incidence and prevalence of ARBD can be derived from a number of sources including:

- Services specifically designed for those with ARBD
- Reviews of admissions to and/or discharges from hospitals
- Studies of rates of ARBD or conditions falling within the ARBD spectrum within specific populations

3.3.1 Rates for ARBD derived from ARBD-specific services

A specialist Glasgow-based ARBD service reports accepting 3-4 new cases per week and suggests there were over 500 known cases of ARBD in Glasgow in 2012. This suggests an incidence rate of 20/100,000 and a prevalence rate of >56/100,000 in the Glasgow population.²⁵ It should be noted that Scotland has historically experienced high rates of alcohol related morbidity and mortality compared to the rest of the UK.³⁸

A specialist service established within the Cheshire and Wirral Partnership NHS Trust and accepting only referrals of those under 65 reported around three new

referrals per month in 2013, suggesting an annual incidence of 13.9/100,000 amongst under 65 year olds.³⁹

3.3.2 Rates for ARBD derived from general hospital admissions/discharges

The numbers of people seen in hospitals or other care settings in relation to specified conditions can provide some evidence for the incidence and prevalence of ARBD. However, hospital admission and discharge data can be difficult to interpret, given problems such as underdiagnosis and coding (see section 2.2). Studies using these data have suggested a wide range in prevalence rates.

- Unpublished studies from Glasgow and Argyll and Clyde in Scotland, areas with high rates of alcohol-related mortality,⁴⁰ suggest prevalence rates of ARBD in 2003 between 38/100,000 and 144/100,000 in those areas^{1,2}
- An Australian study calculated the annual rate of hospital admissions for ARBD in 1996-7 as 15/100,000. The rate was 23/100,000 for men and 12/100,000 for women⁴¹
- A study across several health board areas in Northern Ireland and the Republic of Ireland suggest a rate of hospital admissions of 14/100,000⁴² in 2011

3.3.3 Rates of conditions within the spectrum of ARBD

Evidence on the prevalence of conditions that fall within the spectrum of ARBD includes studies reporting that:

- Alcohol-related dementia accounted for 10-24 per cent of all dementias amongst care home residents and 3-5 per cent of dementias diagnosed in neurology and memory clinics (review of evidence from several countries)⁹
- Prevalence of alcohol-related dementia was 8.3/100,000 in the 30-64 year old population, (95% CI 4.7-13.4); 12.5 per cent of all young onset dementia cases were alcohol related dementia (London)⁴³
- Of young onset dementia cases, 12.3 per cent were alcohol related (Lothian, Scotland)⁴⁶
- Prevalence of alcohol related dementia amongst over 50s newly admitted to hospital was 1.4 per cent across all patients with dementia but 22 per cent for those under 65 (Australia)⁴⁴
- Significantly more care home residents with early onset dementia had the condition as a result of alcohol than residents with dementia onset after 65 (USA)⁴⁵
- Annual incidence for KS amongst admissions to a psychiatric hospital and a general hospital rose from 1.3/100,000 in 1990 to 8.1/100,000 in 1995 (Glasgow).²⁸ The authors suggest this substantial increase was the result of better diagnosis and issues limiting the injecting of thiamine.²⁸ These issues are discussed in detail in Section 4 below.

- Numbers of patients diagnosed with KP amongst those in psychiatric care in Scotland rose from 48 to 110 between 1982 and 1988⁴⁶
- The prevalence of KP amongst long stay psychiatric inpatients suggested a rate of 3.5/100,000 across the Scottish population, but with significant regional variation⁴⁰
- Review of hospital admissions suggested a prevalence for WKS of 6.5/100,000 (Australia)⁴⁷

3.3.4 Current prevalence and epidemiology in Wales

Given the challenges of estimating the current prevalence of ARBD, a robust estimate of the number of people in Wales with ARBD is beyond the scope of this report. Following the methodologies of recent studies using hospital admission figures^{41,42} it has been possible to examine the trends in Welsh patients diagnosed with ARBD related conditions in hospitals.

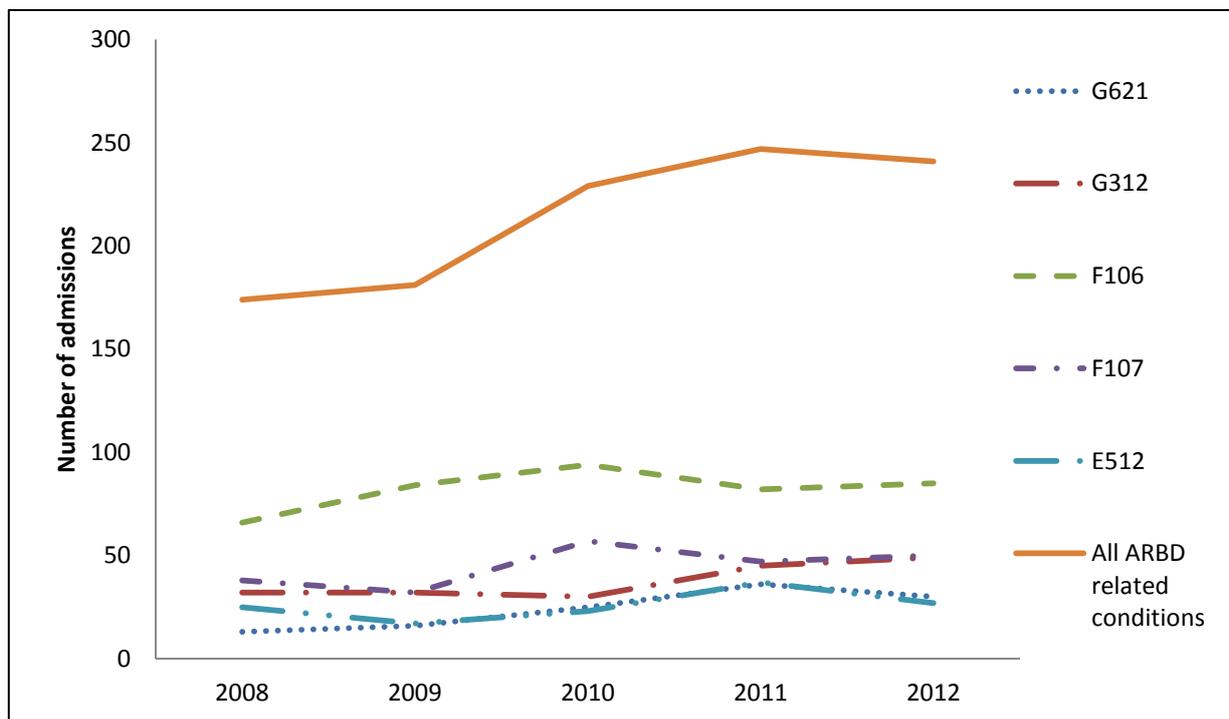
Table 1 describes the ICD-10 codes (clinical codes that are assigned to patients when they are diagnosed) that have been used to identify ARBD patients admitted to hospital in 2012. With the exception of WE (which is most usually observed in those who drink hazardously or are alcohol dependent, but which can arise solely through malnutrition) this list uses only conditions which are entirely caused by alcohol. This is therefore a more conservative list than some previous studies.⁴² As these individuals / patients were recorded on admission to hospital, the numbers presented in Table 1 are assumed to represent patients at the more severe end of the ARBD spectrum.

Table 1: Hospital admissions (Welsh residents) with ARBD-related conditions (any mention) in 2012

ICD-10 code	Description	Admissions 2012
E51.2	Wernicke's encephalopathy (WE)	27
F10.6	Alcohol amnesic syndrome (KP/KS)	85
F10.7	Alcohol related residual and late-onset psychotic disorder	50
G31.2	Degeneration of nervous system due to alcohol (includes cerebellar atrophy)	49
G62.1	Alcoholic polyneuropathy	30
Total		241

Source: PEDW 2014

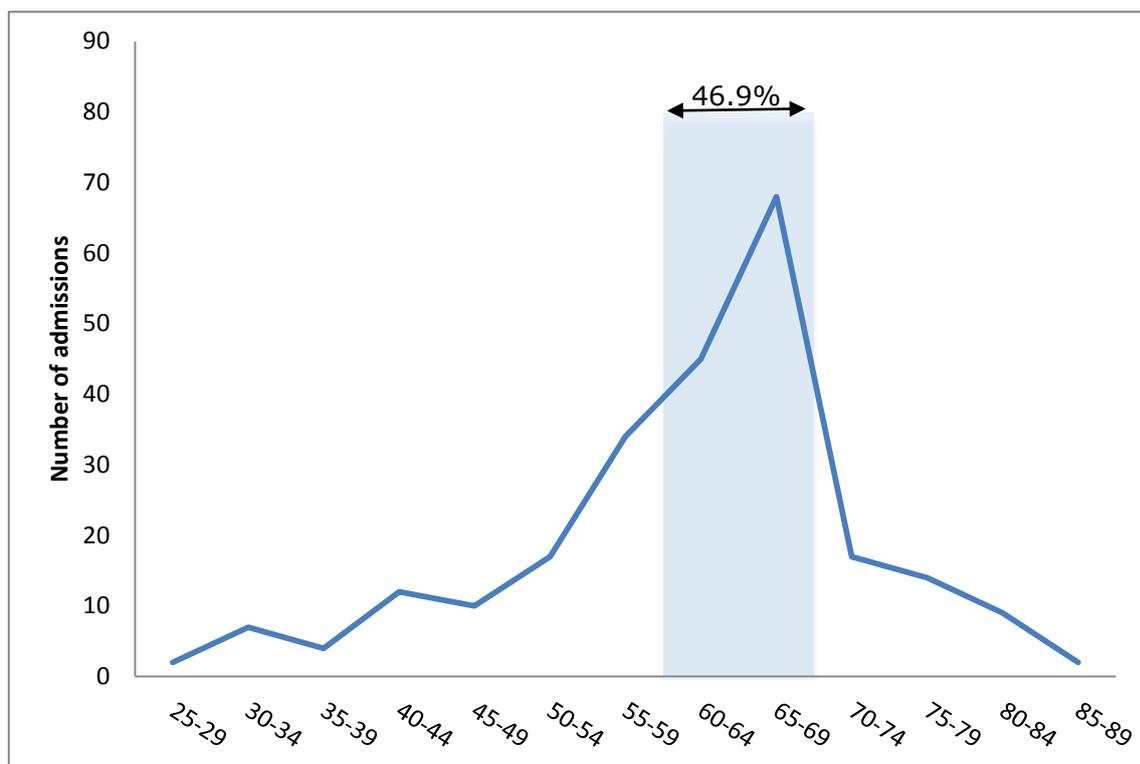
Variation exists in the number of patients admitted to hospital over the period 2008 to 2012 across the different conditions described in Table 1. Chart 1 indicates the trend in hospital admissions, with one or more of the codes detailed in Table 1, between 2008 and 2012.



Source: PEDW 2014

Chart 1: Hospital admissions (Welsh residents) with ARBD-related conditions (any mention) 2008-12.

Over the five year period (2008-12), there has been a general upward trend in the numbers of Welsh residents diagnosed with ARBD-related conditions representing an overall increase of 38.5 per cent. The increases were observed across ARBD-related conditions, however, there was variation in the scale of these increases, from 8 per cent (WE) to 131 per cent (alcoholic neuropathy). The reason or reasons for these variations cannot be inferred from the data alone and may include; an increase in admissions of patients with ARBD, greater awareness of alcohol-related conditions or more accurate diagnosis of ARBD-related conditions. Further evidence is required to identify longer term trends and better interpret this data.



Source: PEDW 2014

Chart 2: Welsh residents admitted to hospital with ARBD-related conditions (any mention), 2012, by age group

Chart 2 shows that those diagnosed with ARBD-related conditions are most frequently in the 65-69 year age band, followed by the 60-64 age band. These two age bands account for almost half (46.9 per cent) of all those diagnosed in 2012. As described in section 3.1, services typically report a mean age of 50-60 for ARBD patients accessing specialist treatment when specialist ARBD training and referral tools are in place.^{12,25} As such, the admissions data suggest that in Wales it is likely that a younger cohort of individuals with ARBD may remain undiagnosed until more severe symptoms are presented.

Calculating survival rates of those diagnosed with ARBD using different ages (i.e. assuming that everyone diagnosed with ARBD lives to a specified age) produces an estimate of the total number of ARBD patients who have ever been diagnosed and hospitalised. These estimates, with a range of assumed average ages of death, and using the mean age within each age band for calculations, are shown in Table 2.

Table 2: Estimated number of Welsh residents with ARBD who have been diagnosed and hospitalised under different assumptions of average age at death

Assumed average age of death	Estimated number of ARBD patients
75	3,251
70	2,365
65	1,643
60	1,101

The need for a more robust methodology to underpin further research into the prevalence and epidemiology of ARBD in Wales is specified in the recommendations sections

4 Preventing ARBD: the prescribing of thiamine

4.1 Thiamine prescribing: key issues

The role of thiamine in preventing ARBD is well established. However, the evidence suggests that developments in policies and guidance around thiamine prescribing over the past 25 years may have led to substantial under-prescription in some settings.

The evidence base for thiamine administration (oral and injectable) in the prevention and treatment of ARBD was reviewed as part of the development of NICE clinical guidelines for diagnosis and clinical management of alcohol disorders, 2010. This review found only five published studies, with a total of 261 participants. Only one of these studies had a follow-up period of longer than one week.⁴⁸ In particular, the authors noted a lack of consistent evidence or clear guidance on how to identify those at risk.⁴⁸ The review recommended that those drinking at harmful or dependent levels who were also malnourished, withdrawing from alcohol or admitted to hospital for acute illness should be considered at 'high risk'.⁴⁸

In addition, it was recognised that many of those who were 'high risk' will have lifestyles that mitigate against the taking of oral thiamine as prescribed, or its absorption by the body when taken.⁴⁸ The formal clinical guidance was that injectable thiamine be offered to 'harmful or dependent drinkers' if they were malnourished and were treated in A&E or admitted to hospital with an acute illness.⁴⁸ Previous guidelines issued by the British Association of Psychopharmacology in 2004 also highlighted low rates of oral thiamine absorption in malnourished patients (potentially less than 1mg of a 30mg tablet) and recommended that all those diagnosed with, or at risk from, WE should have intramuscular or intravenous thiamine.⁴⁹

Prior to 1989, the most common injectable thiamine preparation was Parentrovite.⁵⁰ However, following concerns over the risk of cardiac arrest and anaphylactic shock,⁵¹ Parentrovite was withdrawn and Pabrinex, an alternative injectable preparation was licensed for use.^{52,53} However, guidelines recommended that thiamine only be injected where resuscitation equipment was available¹⁹ highlighting the risks of adverse reactions. Numerous reports in the 1990s and early 2000s suggested that many practitioners had stopped administering parenteral thiamine completely.^{19,28,50,52,53}

4.2 Thiamine prescribing in Wales: trends and comparisons with other parts of the UK

4.2.1 Prescribing in general practice

Full year prescribing data from GP practices is available from 2003. It has therefore not been possible to explore longer term trends including the periods in which concerns over the safety of thiamine injecting were initially raised and addressed. It should be noted that thiamine may be prescribed in the community by specialist agencies carrying out specific procedures such as home detoxification and that these prescriptions may not be included in GP prescribing data, as such the data in this section may be incomplete.

In 2012, injectable thiamine was prescribed 89 times across the whole of Wales within GP practices. This figure represented a fall of more than 50 per cent on the previous year, which, with 198 prescriptions, represented a peak for the period 2003-12. Over the same period, oral thiamine prescriptions have more than doubled from 128,618 in 2003 to 302,554 in 2012, with consistent year-on-year increases. These trends in thiamine prescribing are shown in Chart 3.

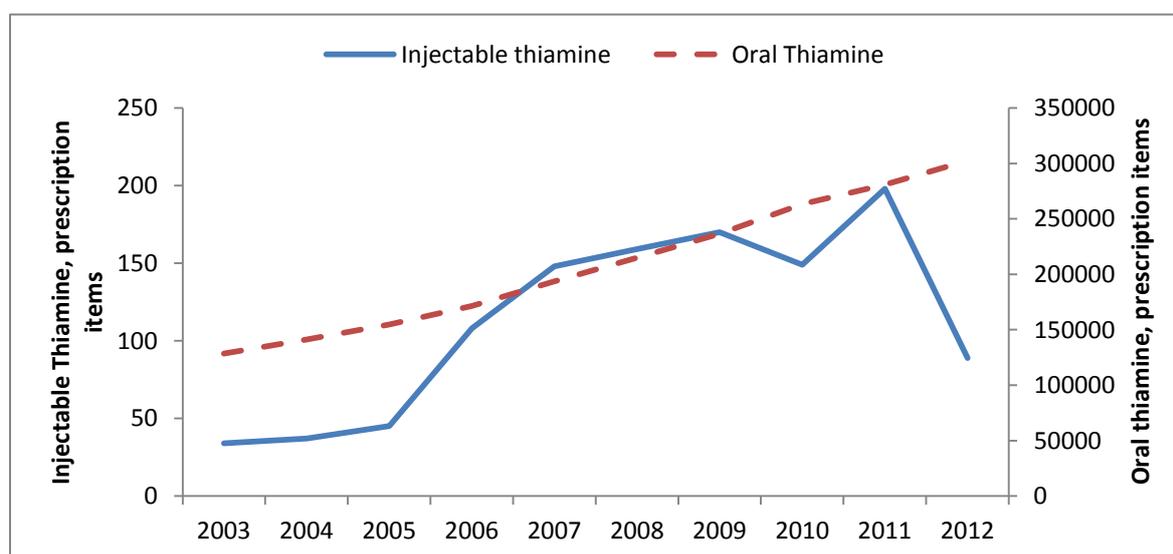


Chart 3: Total items of injectable and oral thiamine prescribed in primary care in Wales, 2003-12

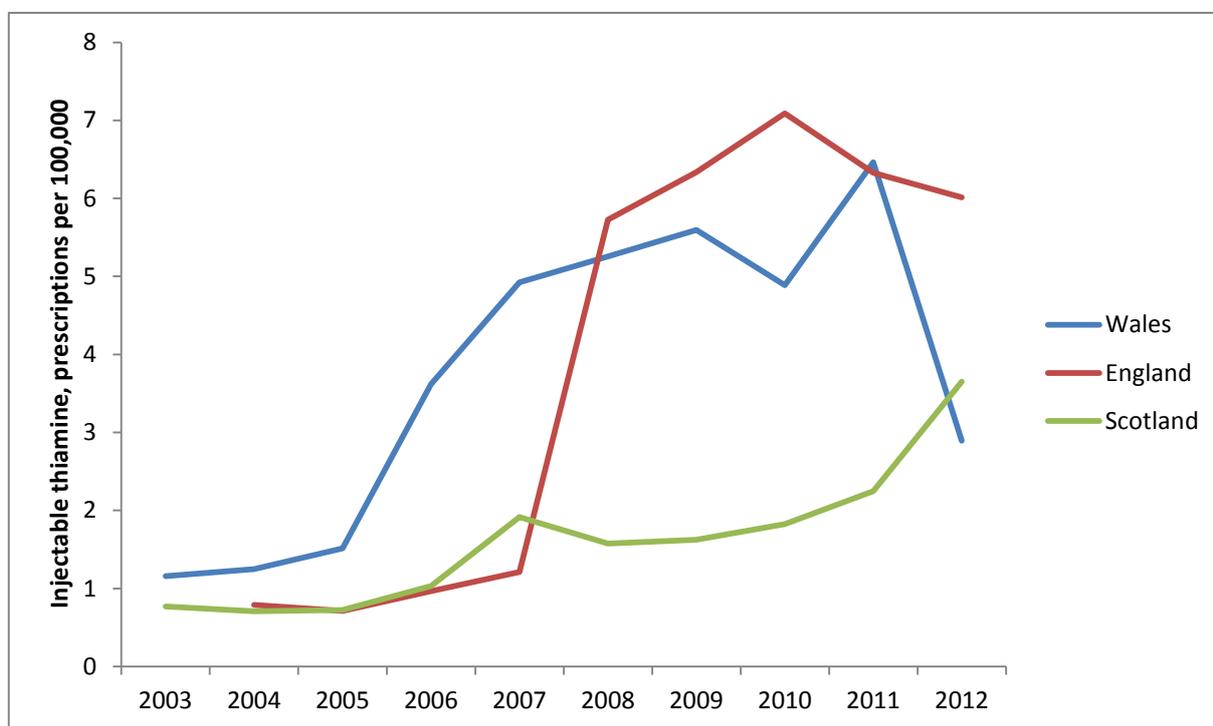
Source: NWIS 2014

In 2012, rates of prescribing per 100,000 population for injectable and oral thiamine in the UK were:

Country	Injectable thiamine	Oral thiamine
Wales	2.9	9,840
England	6.0	7,608
Scotland	2.8	5,532

Source: NHS Wales Primary Care Services; NHS Information Centre for Health and Social Care; NHS National Services Scotland

However there has been considerable variation over time. Primary care prescribing rates for injectable thiamine in Wales, England and Scotland between 2003 (2004 in England) and 2012 are shown in Chart 4. Prescribing figures for England indicate that GPs have been reporting the renewed prescribing of Parentrovite since 2008, although in very low amounts (2.7 per cent of all prescribing of injectable thiamine in 2012). The reasons for this are not known at present.



Source: NHS Wales Primary Care Services; NHS Information Centre for Health and Social Care; NHS National Services Scotland, Information Services Division; ONS 2014

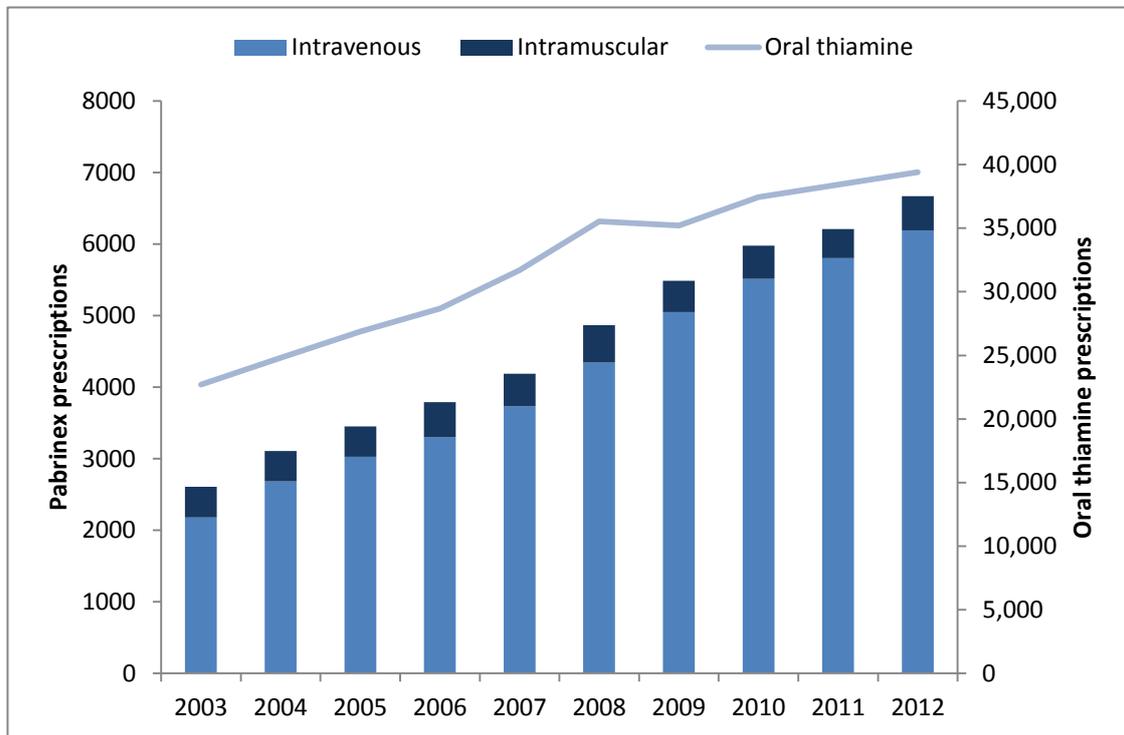
Chart 4: Crude rate of prescribing of injectable thiamine in primary care, per 100,000 population, Wales, England and Scotland, 2003-12

In addition, there is considerable variation in thiamine prescribing between GP practices in Wales. In 2012 only 19 out of 549 Welsh GP practices reporting in Wales prescribed injectable thiamine and only six prescribed more than once. A single GP practice accounted for 45 prescription items, more than half of the total number.

Analysis of the types of thiamine prescribed by GPs in Wales over this period shows that the mean milligrams per prescription of oral thiamine rose by 16.7 per cent to 702 milligrams between 2003 and 2012, suggesting that GPs are, in general prescribing higher doses to those perceived as being 'high risk' in the community.

4.2.2 Thiamine prescribing in hospitals in Wales

Full year data is available for hospital prescribing in Wales from 1998. As such, accounts of changes in injectable thiamine prescribing in hospital environments in the 1990s could not be evaluated. Chart 5 represents the trend in injectable thiamine (pabrinex) and oral thiamine prescribing in hospitals over the period 2003 to 2012.



Source: NWIS

Chart 5: Hospital prescriptions for injectable thiamine (Pabrinex) and oral thiamine in hospitals in Wales, 2003-2012

There is a consistent upward trend in the hospital prescribing of Pabrinex over the period, with a 2.5-fold increase in prescribing frequency over the period, to 6,669 prescriptions in 2012. The data also indicate that the proportion of Pabrinex injections that are intravenous rather than intramuscular has increased from 83.6 per cent to 92.9 per cent over the period. The prescribing of oral thiamine in hospitals has risen 74.8 per cent between 2003 and 2012 from 22,270 to 38,927 items.

Whilst the evidence shows a trend of increased prescribing of injectable thiamine in hospitals and in the community over the past ten years, these levels are rising from a low base which may be the result of historic safety concerns. Thiamine prescribing in Primary Care remains very low in relation to the number of people

in Wales who are likely to be at risk of ARBD. These issues are addressed further in the recommendation section.

5 Services for those with ARBD: contexts, challenges and models

5.1 Rehabilitation: evidence and obstacles

ARBD is a potentially reversible condition. The best available evidence suggests that ARBD outcomes, following abstinence and structured rehabilitation, are; complete recovery for 25 per cent of patients, significant recovery for a further 25 per cent, slight recovery for 25 per cent, with the remaining 25 per cent showing no recovery.²³

However, although these figures are endorsed by a number of experienced specialist practitioners,⁸ it should be noted that:

- Many of the available studies are several decades old⁶
- Many studies fail to provide clear definitions of 'recovery' or detail any interventions^{54,55}
- Many studies were carried out in locations that may not generalise well to Wales.

The need for clearer definitions and further research in this area is detailed in the Recommendations section.

The historical lack of a clear and agreed definition of ARBD has meant that appropriate services, both social and clinical, have not been developed to meet the needs of ARBD patients. Examples of ARBD patients 'falling through the gaps' or being 'passed from pillar to post' are common in the literature.^{24,31} In some cases, the issue is a 'revolving door' of frequent short term admission and discharge to inappropriate settings.²⁹ Even when clinicians identify the need for specialist accommodation and care it may not be available for the majority of ARBD patients.²⁶ Significant gaps in appropriate services that can support effective rehabilitation have been reported by voluntary sector care providers in the UK at least since the 1990s.³¹

When residential services are found for ARBD patients, it is often within accommodation intended for older adults with dementia or similar conditions and lacking in appropriate ARBD specific support. Clinical and psychological studies have found evidence that placing ARBD patients in long term residential care designed for older people with progressive illnesses can lead to further cognitive and/or social deterioration.^{2,13,56} Research has shown that ARBD patients themselves are often aware that their needs are not being met and find the lack of involvement in their own care choices frustrating.^{13,24} These services may find managing ARBD patients, who may exhibit disinhibition and aggression that are not characteristic of other care home residents,⁸ challenging to work with.

Even in care home settings where staff have specialist training around the needs of those with cognitive impairment, knowledge of ARBD is often limited.⁵⁷ The need for general workforce development for frontline staff working with ARBD clients has also been identified.²⁹ Social stigma which patients may have experienced prior to engagement with services may continue into residential settings.²⁴

5.2 Service models

Where specialist services have been established, there have been measurable positive outcomes in rehabilitating those with ARBD. However, these services are often designed to support abstinent patients in the later stages of ARBD. There is a need for service development that includes those patient who are unwilling to become abstinent (see Recommendations section).

A review of best practice in ARBD services in Scotland has suggested a tripartite classification of ARBD patients into:

- those who are slow to recover (and who therefore need specialist support and accommodation with 24 hour care)
- those who have stopped drinking and are open to intervention (who need supported accommodation with social and clinical support)
- those who continue to drink and resist intervention (who require outreach services, including access to injectable thiamine, and possible crisis intervention).²⁹

The service established within the Cheshire and Wirral Partnership Trust is one example of a specialist service that has been successful in supporting ARBD patients to recover. The Wirral service reports that, of 41 referrals accepted into the service (69 per cent of whom required residential support initially), 17 patients (41.5 per cent) reached a point at which further cognitive improvement was considered unlikely and were resettled.¹² The service has calculated that providing specialist support resulted in an 85 per cent reduction in inpatient days per patient per year.¹²

Although the evidence base for specific techniques to improve the cognitive capabilities of ARBD patients is not well developed,²³ the literature consistently describes a need for multidisciplinary approaches to rehabilitation, including social support, ongoing clinical assessment and occupational therapy.^{8,13} In particular, the evidence suggests these patients benefit from support to manage their finances, continued abstinence and risks of exploitation by others.¹² Availability of a keyworker with whom they can build a relationship is also typically valued by those recovering from ARBD.²⁴ A number of reviews have

suggested that, rather than modelling care on services for older people with non-alcohol-related dementias, care would be more effective if modelled on services designed to treat head injuries.^{13,58} Regardless of the regime, it is likely that rates of improvement will differ across different neurological domains.⁵⁹

For those who require residential care, the evidence indicates a period of two to three years will be required before patients are likely to be able to re-integrate into the community.^{8,12} However, with abstinence, some level of recovery can often be observed within 3 months.^{8,12}

At a regional and national level, the literature provides a number of examples of best practice and guidance for service organisation. Neuropsychiatric services have been identified as having the skills and the capacity to take on the management of ARBD patients.⁶⁰ Cardiff is one of a relatively small number of cities within the UK which has a specialist neuropsychiatry service.

Where resources are not available to provide a full range of ARBD service within a single institution, private sector residential provision in which staff have experience of working with younger patients with non-progressive brain injuries may be appropriate to supplement existing services.

5.3 Current provision for ARBD patients in Wales

Given the prevalence estimates of ARBD, and the likely proportions requiring appropriate residential care for rehabilitation in Wales, there is not adequate capacity at present in Wales to meet the needs of existing and future ARBD patients.

Data from the Care and Social Services Inspectorate Wales (CSSIW) suggests that only a small number of residential care homes in Wales provide services specifically for those with ARBD. The Arbennig Unit in Colwyn Bay is a 21 bed unit supporting those diagnosed with KS. Carezza Care also provides places for residents including those diagnosed with KS in four care homes in North Wales. Within Cardiff, those with ARBD who are supported by social services and who require residential care are placed in specialist care homes in England at a cost of £770 per week.

The CSSIW provided current figures for care homes that cater for those with brain injury which, as described above, may provide a more appropriate setting for patients with ARBD who need rehabilitative care.

Table 3: Number of registered care homes and available places for adults under 65 with a brain injury in Wales

		CSSIW Region			Total
		North Wales	South East Wales	South West Wales	
Care homes	Homes	1	4	10	15
	Places	40	29	100	169
Care homes with nursing	Homes	0	3	1	4
	Places	0	49	26	75
Total	Homes	1	7	11	19
	Places	40	78	126	244

Source: CSSIW, 2014

As at September 2013, there were 1,135 regulated adult care homes in Wales providing 26,335 places. However, as indicated in Table 3, only 244 places potentially suitable for those with ARBD were available and these are unevenly distributed around Wales. All care homes are in the private sector.

There is a need for further research into the availability of appropriate accommodation for both ARBD patients who require full time residential care and those who would need supported housing or support to maintain living in their own homes.

6 Recommendations

Theme 1: Prevention

Recommendation 1

Raise awareness of the signs and symptoms of ARBD amongst the general population, clinical and social care professionals and paid and voluntary care service personnel who may be engaged with those who have, or are at risk of developing, ARBD.

Recommendation 2

Engage with the clinical community responsible for prescribing thiamine to support understanding of, and effective adherence to, clinical guidelines in relation to injectable thiamine. Review, and as necessary promote the updating of clinical guidelines on the prescribing of thiamine.

Theme 2: Early detection, diagnosis and engagement

Recommendation 3

Develop, evaluate and implement national ARBD-specific diagnostic test/s, and associated training, for initial assessment and diagnosis of ARBD. Ensure all relevant health and social care practitioners are fully trained and competent to assess.

Recommendation 4

Promote early engagement and provision of appropriate psychosocial and pharmacological interventions for hazardous and dependent drinkers in the community to reduce actual and potential harms in relation to alcohol and ARBD, including amongst those who are not currently considering abstinence.

Recommendation 5

Ensure timely referral, through clear care pathways, to specialist assessment, treatment and rehabilitation services with the support of an identified lead ARBD clinician within each Health Board area in Wales. This should be included within the Welsh Government's Substance Misuse Treatment Framework

Theme 3: Treatment and support services

Recommendation 6

Ensure that a comprehensive multi-disciplinary care plan and risk assessment is developed with each patient including those diagnosed with ARBD and not abstinent from alcohol.

Recommendation 7

Identify and liaise with established ARBD services across the UK to better understand how services and resources have been effectively configured to meet the needs of ARBD patients and develop effective service model for Wales.

Recommendation 8

Assess current capacity and options for addressing the treatment and rehabilitation needs of ARBD patients within Wales and quantify existing and future unmet need and associated costs.

Theme 4: Establishing a robust evidence base

Recommendation 9

Establish accurate prevalence figures and epidemiological profiles for ARBD patients and those at 'high risk'.

Recommendation 10

Develop the evidence base regarding outcomes of different approaches to managing rehabilitation of ARBD, including clear, consistent and relevant definitions of 'recovery' and 'rehabilitation'.

Recommendation 11

Better evidence the effectiveness of injectable thiamine administration in the community for preventing and/or treating ARBD amongst vulnerable populations.

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