



Assessment of Incidences of Alcohol-Related Brain Injury (ARBI)

in the HSE West (Donegal, Sligo, Leitrim) and Western Health and Social Care Trust Areas.

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1. Introduction

This report sets a summary of the work undertaken to identify the incidences of Alcohol-Related Brain Injury (ARBI) in the HSE North West and Western Health and Social Care Trust areas, together with an analysis of the findings. The report is structured as follows:

Section 1 – Introduction

This section presents an introduction to the North West Alcohol Forum and the work undertaken, noting the terms of reference.

Section 2 – Introduction to Alcohol-Related Brain Injury

This section provides an overview of the nature of ARBI and the conditions specified as ARBI for the purposes of this research.

Section 3 – Literature Review

This section sets out a summary of the literature reviewed as part of the desk-top research into the prevalence, assessment, treatment and care of people with ARBI.

Section 4 – Policy Approach to ARBI

This section provides an overview of the strategic context and policy drivers for ARBI services within the Republic of Ireland and Northern Ireland.

Section 5 – Local Context – Incidence of ARBI

This section sets out the methodology for the collection of data in relation to ARBI, the key findings and analysis of the data and summarises local consultations to outline the current care pathways for people with ARBI.

Section 6 – Conclusions and Recommendations

This section sets out our conclusions in relation to the information gathered and analysed, and presents our recommendations for ARBI.

1.1 North West Alcohol Forum Ltd

The North West Alcohol Forum Ltd (NWAF) was established in 2007 as a community not-for-profit initiative aimed at reducing alcohol related harms in the North West of Ireland. NWAF works in partnership with statutory, voluntary and community agencies and organisations across the community, health, education and justice sectors. The aims of the NWAF include:

- Recognising the importance of multi-sectoral action and the pivotal role of local communities in developing mutually accepted comprehensive policies and programmes for the prevention and management of alcohol related harm
- Promoting community mobilisation as an effective approach in tackling alcohol related harm within our local communities
- Ensuring effective implementation of evidence-based action to prevent the health risks and socio-economic problems often associated with harmful and hazardous alcohol consumption on the island of Ireland
- Within the island of Ireland inviting inter-governmental and non-governmental organisations to join forces in collective action thereby maximising and contributing to a border-wide effort in reducing harmful and hazardous alcohol consumption and related health and social problems.

NWAF has focused on supporting communities in dealing with alcohol-related issues. In addition, NWAF has taken an advocacy and lobbying role on the issue of alcohol-related harm.

The rise of alcohol consumption in Ireland and Northern Ireland, increases in binge drinking, greater youth access to alcohol and increased presentations with alcohol-related issues suggest a potential growth of ARBI in this region (section 2 provides an overview of ARBI). Whilst not a treatment provider, NWAF is concerned about the growth of this problem and has agreed to initiate, facilitate and lead appropriate inter-agency/inter-disciplinary discussions to develop awareness of ARBI, assess the current issues presenting in the north west, discuss possible actions to address any care pathway or support problems for sufferers and develop recommendations for a regional/national plan on ARBI.

1.2 Terms of Reference

The terms of reference for this work were set out in the invitation to tender as follows:

- To research the number and frequency of ARBI cases appearing in the target area in the last five years using available data from HSE, WHSCT and hospitals in the target area.
- To profile the change in the levels of recorded cases over that time
- To provide an overview of care pathways that are offered to these patients
- To report on best practice in ARBI from other regions within the island of Ireland and beyond
- To explore the initial possibility for shared care on a cross-border basis.

This report was compiled on behalf of NWAF Ltd by Moore Stephens Consultancy.

2. Introduction to Alcohol-Related Brain Injury

This section provides an overview of what is meant by Alcohol Related Brain Injury. Section 3 provides a more detailed analysis of treatment for this condition as evidenced from the literature review.

2.1 Overview

Alcohol Related Brain Injury (sometimes called Alcohol Related Brain Damage or ARBD) is a term used to describe the physical impairment to the brain sustained as a result of alcohol consumption. Having ARBI is not the same as having an intellectual disability, nor is it the same as having dementia. A number of conditions may be associated with ARBI. For the purposes of this research, the NWAF defined them as follows:

- Cerebellar Atrophy – primarily affecting coordination and causing a wide-based gait
- Peripheral Neuropathy – leading to reduced sensation in feet and legs (and sometimes the hands)
- Hepatic Encephalopathy – severe alcohol related liver disease can cause an acute disturbance of brain function with confusion initially but may develop to coma
- Frontal Lobe Dysfunction – this part of the brain is important for planning and organising, judgement, problem-solving, flexible thinking and behaving in socially appropriate ways
- Korsakoff's Amnesic Syndrome (also called Korsakoff's psychosis) (see section 2.3 for further explanation)
- Wernicke's Encephalopathy (see section 2.2 for further information).

The most commonly associated ARBI are Korsakoff's Amnesic Syndrome and Wernicke's Encephalopathy and are the two conditions which are caused solely by alcohol misuse. Korsakoff's and Wernicke's are two separate but related stages of Wernicke-Korsakoff syndrome.¹

Individuals may also have Alcoholic or Alcohol-Related

Dementia, a condition which may be more common than Wernicke-Korsakoff's syndrome, but which may be misdiagnosed as such. Alcoholic dementia may lead to cerebellar atrophy and frontal lobe dysfunction. A report by the Expert Group on Alcohol Related Brain Damage in Scotland (2004) notes that Alcoholic Dementia is more difficult to diagnose and its existence is a matter of debate – some suggest that it is part of Wernicke-Korsakoff's while others state that Wernicke-Korsakoff's is part of Alcoholic Dementia.

1. Information Sheet, Alcohol-related brain damage, Alzheimer Scotland, 2004

The report notes however that the differences between the two types of brain damage are important as they have different implications for treatment and the progression of the conditions.

2.2 Wernicke's Encephalopathy

Alzheimer Scotland describes Wernicke's encephalopathy as:

... a neuropsychiatric disorder resulting from a lack of thiamine (Vitamin B1) which affects the brain and nervous system. Lack of thiamine is common in heavy drinkers because of their poor eating habits and/or frequent vomiting. In addition, alcohol can cause inflammation to the stomach lining, which interferes with the body's ability to absorb vitamins from food intake.

Wernicke's is not exclusively found in heavy drinkers and thiamine deficiency can also be caused by forced or self-inflicted starvation (such as anorexia nervosa), malnutrition, some kidney problems and severe vomiting during pregnancy. The condition has also been found in some patients with AIDS.²

A person with Wernicke's encephalopathy will typically have the following:

- Global confusional state resulting in severe disorientation and difficulty retaining new information
- Ataxia, which causes someone to walk with his or her feet spread wide apart. They may be unable to walk safely if severely affected
- Disturbance of the muscles controlling eye movements leading to an inability to move the eyes normally and involuntary jerking movements of the eyes.³

A presentation to the Brain Injury Australia National Conference in 2008 by Dr Mike McDonough, Addiction Medicine Physician at the Western Hospital (Australia)⁴ noted that:

- Wernicke's Encephalopathy is a preventable, potentially severe form of brain damage but may often be 'sub-clinical'

- It is most common in alcoholics in whom Thiamine absorption is poor and some people appear to have genetic vulnerability
- Services generally 'treat' any individuals at risk but are usually uncertain about the accuracy of diagnosis so under-detection is likely to continue.

Thiamine is given either intravenously (IV) or intramuscularly (IM) using the Pabrinex preparation (containing thiamine (vitamin B1), riboflavin (vitamin B2), pyridoxine (vitamin B6) and nicotinamide). NHS guidance recommends that Pabrinex is administered by IV or IM for three days (dosage dependent on whether the treatment is preventative or therapeutic) and then orally for at least three months in abstinent patients with a well-balanced diet or indefinitely for those who continue to use alcohol or who have a poor nutritional intake.⁵ Given the risk of anaphylactic shock from repeated doses of high concentrations of thiamine, it is recommended that thiamine administered by IV and IM is only carried out in locations with facilities (medically supported) for treating anaphylaxis (thus making it more difficult for this to be given in this way as part of a home detoxification).

2. Information Sheet, Alcohol-related brain damage, Alzheimer Scotland, 2004

3. A Fuller Life: Report of the Expert Group on Alcohol Related Brain Damage, Scottish Executive, University of Stirling and Dementia Services Trust, 2004

4. McDonough Dr M, Wernicke's Encephalopathy: A Continuing Diagnostic Problem, <http://www.arbias.org.au/general-category/download-2.html>, 2008

5. NHS Fife, Wernicke's Encephalopathy and Thiamine Supplementation for Alcohol Dependent Patients, 2007,

<http://www.fifeadtsc.nhs.uk/support/Pabrinexflowdiagramfinal.pdf>

2.3 Korsakoff's Amnesic Syndrome

Whilst Wernicke's can be considered the acute form, Korsakoff's is the chronic form (in that it is not easily or quickly resolved). Alzheimer Scotland highlights that, if Wernicke's is left untreated, Korsakoff's may result; although it also notes that Korsakoff's may occur without Wernicke's preceding.⁶

People with Korsakoff's Syndrome will typically have the following difficulties:

- A profound difficulty in learning new information. As time passes this results in an increasing period of time for which the individual has little or no memory
- The individual does not have an immediate memory and so can recall new information for a very short time
- Things learned prior to developing Korsakoff's are remembered normally

- Individuals tend to fill in the gaps in their memory with erroneous material
- Individuals may show a lack of motivation or initiative.⁷

The memory loss described above is the most significant feature of Korsakoff's – with many other abilities remaining unaffected. Alzheimer Scotland notes that this is where Korsakoff's differs from most types of dementia where there is often damage to a large area of the brain cortex and where a much wider range of abilities are affected.⁸

Typically Korsakoff's affects men aged between 46-65. Women can also be affected but it is noted that they tend to develop the condition at a slightly younger age, on average ten years earlier than men.⁹

Key Points

- The conditions covered by ARBI for the purposes of this report are:
 1. Cerebellar Atrophy – primarily affecting coordination and causing a wide-based gait
 2. Peripheral Neuropathy – leading to reduced sensation in feet and legs (and sometimes the hands)
 3. Hepatic Encephalopathy – severe alcohol related liver disease can cause an acute disturbance of brain function with confusion initially but may develop to coma
 4. Frontal Lobe Dysfunction – this part of the brain is important for our ability to plan and organise, judgement, problem-solving, be flexible in thinking and behave in socially appropriate ways
 5. Korsakoff's Amnesic Syndrome – leading to difficulty in learning new information, memory loss and confabulation
 6. Wernicke's Encephalopathy – caused by a lack of thiamine (Vitamin B1) and which causes confusion, ataxia and disturbance of the muscles controlling eye movements.
- Wernicke's can be considered the acute form and Korsakoff's the chronic form of ARBI.
- Wernicke's Encephalopathy is preventable but if left untreated, Korsakoff's may result.

6. Information Sheet, Alcohol-related brain damage, Alzheimer Scotland, 2004

7. A Fuller Life: Report of the Expert Group on Alcohol Related Brain Damage, Scottish Executive, University of Stirling and Dementia Services Trust, 2004

8. Information Sheet, Alcohol-related brain damage, Alzheimer Scotland, 2004

9. Information Sheet, Alcohol-related brain damage, Alzheimer Scotland, 2004

3. Literature Review

This section provides a summary of our desk-top review for national and international literature in relation to ARBI and includes the following sub-sections:

- Overview
- Prevalence
- Assessment and Diagnosis
- Intervention
 - Alcohol Detoxification
 - Service Response
- Acquired Brain Injury
- Examples of good practice.

Our research has noted that there do not appear to be a large number of studies or research reports into ARBI, particularly in Ireland. Those that we have noted have primarily been developed in Scotland and Australia. Research in Scotland appears to have been comprehensive but dates from 2003/04 and further research would be required to determine how much of an impact this has had on current services.

3.1 Overview

ARBI is often described as the invisible condition.¹⁰ It is a condition which is complex in its nature, is far-reaching in its implications for the individuals involved, and challenging and costly to the health and social care system in terms of interventions including treatment and support.

ARBI is associated with non-traumatic brain injury brought about by factors leading to a degeneration of physical and mental well-being. This is distinguished from injury brought about by physical trauma, known as acquired brain injury (ABI).

The recovery outcome for people with ARBI is thought to be split into quarters (Smith and Hillman, 1999¹¹):

- 25% making a complete recovery
- 25% making a significant recovery

- 25% making a slight recovery
- 25% making no recovery.

Whilst some people with ARBI do therefore have the potential to recover – either substantially or completely – this requires the condition to be managed in a coordinated way and in appropriate environments, ideally free from alcohol. The issues of abstention from alcohol and associated problems of detoxification are significant challenges in designing treatment and care programmes. This factor distinguishes ARBI from most forms of dementia or brain injury, where recovery is unlikely, and makes early identification a priority.¹²

As highlighted in the report by Scottish Executive, *A Fuller Life*, (2004) and by a number of the health professionals interviewed as part of our research, a key dimension to ARBI is the stigma that can be attached to the condition, often as a result of its triple association with alcohol, mental health problems and dementia. The literature shows that these issues cut across an individual's social as well as physical and mental health capabilities. The consequences of this can be very real for the individuals in terms of the difficulties they experience in securing accommodation (landlords and organisations providing housing, supported or hostel accommodation may not accept people who abuse alcohol due to difficulties in maintaining tenancies or disruption caused to other residents), maintaining employment and maintaining daily living. *A Fuller Life* (2004) suggests that issues raised by the stigma attached to ARBI need to be addressed holistically at an individual, institutional and societal level.

10. Report of the Expert Group on Alcohol-Related Brain Damage: *A Fuller Life*, Scottish Executive, 2004

11. MacRae R, Cox S, Meeting the Needs of People with Alcohol Related Brain Damage: A Literature Review on the Existing and Recommended Service Provision and Models of Care, University of Stirling, 2003

12. Report of the Expert Group on Alcohol-Related Brain Damage: *A Fuller Life*, Scottish Executive, 2004

3.2 Prevalence

Available information on the incidence and prevalence of ARBI nationally and internationally is difficult to establish because of the differences in systems for capturing and recording information. Difficulties have also been identified in the clinical coding of hospital admissions. Admissions to hospital are coded using the ICD-10¹³ classification system. A recent report on *Intensive Support in Reducing Alcohol-Related Hospital Admissions*¹⁴ (September 2010) noted that “clinical coding has emerged as a major issue in relation to alcohol-related hospital admissions. Specifically, there does not appear to be any guidance for clinical coders on how to code alcohol-related hospital admissions. There is also a perception that clinical coders may not be aware of the attributable fractions attached to ICD codes and their role in the rate of alcohol-related hospital admissions.” The report goes on to highlight that a study is being planned to look at current clinical coding practice in major London hospitals with a view to constructing and piloting a set of guidance in coding alcohol-related admissions.

Despite the difficulties in precise quantification of the incidence and prevalence, the literature we reviewed highlights that there are signs of an overall increase in the number of people with ARBI.¹⁵

ARBI can be associated with poor nutrition as well as a range of physical and mental health problems, and there is evidence of a concentration of ARBI in areas of high socio-economic deprivation¹⁶. In addition, people with ARBI are often socially-isolated, many having incurred social, financial, occupational, physical and forensic difficulties as a consequence of years of problematic drinking.¹⁷

In 2000 a report entitled *Comparative Spatial Deprivation in Ireland: a Cross Border Analysis* (Oak Tree Press, Dublin) by Cook et al was published. Part of this report considered the border counties in the Republic of Ireland and the border district council areas in Northern Ireland as a distinct region and compares this to the rest of Ireland. Although the area covered is wider than the area defined as the HSE North West and WHSCT, the characteristics are very similar. Cook’s report identified the border region as being more deprived than the rest of Ireland, especially with regard to unemployment, age dependency, economic dependency, housing and low urbanisation.

Other researchers have separately considered deprivation in each jurisdiction. A study entitled *Deprivation and its Spatial Articulation in the Republic of Ireland (2005)*¹⁸ noted that most of Donegal and parts of other border counties were among the most deprived areas in 2002.

In Northern Ireland there are currently 26 local government districts. Five of these are included in the WHSCT area. The Northern Ireland Multiple Deprivation Measure 2010 ranks Local Government Districts from 1 (most deprived) to 26 (least deprived).

The table below shows that three local government districts in the WHSCT are ranked less than 7 out of 26 in deprivation scores; Strabane and Derry are ranked 2 and 3.

- 13. The International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) is a coding of diseases etc as classified by the World Health Organisation. Many health services internationally use the ICD-10 codes for recording data and making resource allocations.
- 14. Currie J, Intensive Support in Reducing Alcohol-Related Hospital Admissions: A Report describing Intensive Support provided to 10 London Primary Care Trusts/Drug and Alcohol Action Team Partnerships, London Regional Alcohol Group, September 2010
- 15. Correspondence in the British Journal of Psychiatry (2009) 194: 287-288 noted that: “The more relevant concept is that of alcohol-related brain damage, where undoubtedly presentations have increased in recent decades, in parallel with rates of alcohol dependency in the UK.”
- 16. Report of the Expert Group on Alcohol-Related Brain Damage: A Fuller Life, Scottish Executive, 2004
- 17. MacRae R, Cox S, Meeting the Needs of People with Alcohol Related Brain Damage: A Literature Review on the Existing and Recommended Service Provision and Models of Care, University of Stirling, 2003
- 18. Haase T & Pratschke J, Deprivation and its Spatial Articulation in the Republic of Ireland, 2005, Area Development Management Ltd

Table 1:

Deprivation Ranking for Local Government Districts in WHSCT

Council	Deprivation Ranking
Limavady	7
Derry	3
Strabane	2
Omagh	17
Fermanagh	22

Source: Northern Ireland Multiple Deprivation Measure 2010

In the Republic of Ireland, a material deprivation index was developed by the Small Area Health Research Unit (SAHRU), based in the Department of Community Health and General Practice, Trinity College Dublin, to measure deprivation at the level of district electoral divisions (DEDs). The SAHRU deprivation index rates indices of material deprivation on a scale of 1 to 10 where 1 is the least deprived and 10 the most deprived.

Table 2:

Material Deprivation Ranking in the North West region

County	Average Ranking
Donegal	8
Sligo	5
Leitrim	6

Source: SAHRU Index of Material Deprivation 2007

Whilst the above table shows the average ranking for each county, there were a significant number of electoral divisions, particularly in Donegal, that ranked most deprived at 9 or 10 on the scale.

As an international comparator for prevalence, the number of people discharged from hospital with ARBI in Scotland in 2006/07 was 540, a rise of 16% on the previous figure taken in 2003/04 of 463 and the west of Scotland now has the highest rate of people suffering from Korsakoff's syndrome in western Europe.¹⁹

Key Points

- The number of ARBI is expected to increase as a result of population trends and changing patterns of alcohol consumption
- There is evidence that the condition is under-diagnosed (Chiang, 2002)
- Identifying the population involved is difficult (MacRae and Cox, 2003)
- Research suggests that ARBI accounts for 10% of the dementia population (Lishman, 1990) and for 12.5% of dementias of people under 65 (Harvey et al, 1998)
- The lack of accurate diagnosis and assessment makes it difficult to conduct epidemiological studies of the incidence and prevalence of ARBI.

Source: A Fuller Life, 2004 and Meeting the Needs of People with Alcohol-Related Brain Damage, 2003, Scottish Executive

19. Bugler, T, Rise in Scots suffering alcohol-related brain damage, The Scotsman, 8 September 2008

3.3 Assessment and Diagnosis

The complexity of ARBI makes assessment of the condition difficult. There is no single cause of ARBI, which usually results from a combination of factors. These include toxic effects of alcohol on brain cells, vitamin and nutritional deficiencies, head injuries and disturbances to the blood supply to the brain²⁰.

Individuals with ARBI may already have a number of pre-existing physical and psychiatric conditions prior to ARBI being diagnosed such as schizophrenia and bi-polar disorder²¹.

Heavy drinkers are not likely to know that they are acquiring problems due to impairment of insight and awareness and are therefore not likely to turn up in the health system until they become sick, although cognitive decline is likely to already have begun.²² Many people with ARBI are therefore identified within hospitals when undergoing treatment for other conditions and the evidence shows that it is particularly important for hospital staff to have training in the identification of the condition in order to put in place effective treatments and in particular preventative measures, such as detoxification, at an earlier stage.²³

Most literature (including the *Report of the HSE Working Group on Residential Treatment and Rehabilitation (Substance Abuse)*, 2007) identifies the four-tier model of intervention²⁴, treatment and care for mental health in general and ARBI in particular. ARBI, by its nature, requires interventions at all levels of the four-tier model. Evidence shows that the assessment which is essential to developing a treatment plan for individuals is made all the more difficult because it is not possible to have an accurate assessment of a person's long-term needs

unless they abstain from alcohol for a significant period of time – from three months of abstinence²⁵ or for up to two years.²⁶ This is a problematic area because people with ARBI find it very difficult to abstain from alcohol, not least because of the degeneration in their cognitive ability. This makes it very difficult to avoid premature assessment leading to inappropriate placement decisions. In addition, early identification of ARBI is difficult if an individual is unable to abstain from alcohol in order to be assessed or is unwilling to accept the need for assessment and intervention.

Despite the difficulties in assessment and diagnosis, literature shows that in order to obtain good outcomes for people with ARBI it is important to take an integrative approach. Given the multi-faceted nature of the condition, it is important that assessment is ongoing, and many of the literature sources researched would argue that this is best facilitated through the model of a specialist worker.

The point of entry to services for people with ARBI can be largely a matter of chance. Existing service boundaries have tended to result in people with ARBI being compartmentalised, for example in either health or social care services. Even in systems such as those within the Republic of Ireland and Northern Ireland where social care and public health services are under the remit of one health service²⁷ the issue of compartmentalisation occurs, as noted by some of the health professionals interviewed as part of our research.

People with ARBI can present to the health and social care systems in a number of phases which impact on the assessment of their needs and the effectiveness of the interventions. Those phases are:

20. Report of the Expert Group on Alcohol-Related Brain Damage: A Fuller Life, Scottish Executive, 2004

21. Ibid, p27

22. Jackson M, Looking Backwards, Looking Forwards: Is Alcohol Related Brain Injury Still the Invisible Disability, 2008

23. Report of the Expert Group on Alcohol-Related Brain Damage: A Fuller Life, Scottish Executive, 2004

24. Tier 1 services are general education and awareness-raising activities, Tier 2 services are early intervention services, Tier 3 services are specialist or intensive intervention services and Tier 4 services are specialist services often provided in a dedicated inpatient or residential unit

25. MacRae R, Cox S, Meeting the Needs of People with Alcohol Related Brain Damage: A Literature Review on the Existing and Recommended Service Provision and Models of Care, University of Stirling, 2003

26. Report of the Expert Group on Alcohol-Related Brain Damage: A Fuller Life, Scottish Executive, 2004

27. As opposed to England where social services are the responsibility of local councils

- relatively recently onset, which can be cared for with good outcomes, resulting in a lesser level of care and support being required
- the second phase is perhaps where the condition becomes more chronic and the aim would be to have a slow and gradual improvement over two or more years
- the next phase would be where people show no signs of improvement at all
- the final phase would be those who are at the end of their improvement and are still significantly impaired, requiring long-term care and support.

Challenges in Making ARBI Assessments

- Individuals may enter services by many different routes
- Assessment may take place at different levels and within different service systems such as hospital teams, age-related agencies or condition-related services
- Assessment may be prolonged owing to the slow recovery process and individuals may find it difficult to maintain their engagement
- Continued alcohol intake will render many formal assessments invalid, because true cognitive function will be impaired
- Many people with ARBI have co-existing physical or mental health problems
- Due to the impact on cognitive functioning it may be difficult to gain informed consent for the assessment process
- It may also be difficult to gain accurate information from the individual
- The gathering of information from different agencies is important but may be difficult because of different systems and confidentiality policies

Source: A Fuller Life, 2004 and Meeting the Needs of People with Alcohol-Related Brain Damage, 2003, Scottish Executive

A review of the literature and evidence indicates that there does not appear to be a standard screening tool for ARBI, because of the various forms of the condition and the symptoms displayed by individuals. The full assessment and diagnosis of ARBI involves a stepped approach involving mental health assessment skills, specialist psychology and psychiatry, neuropsychology and neuropsychiatry and imaging tests.²⁸

There have been a number of research studies which have used a combination of screening tools. For example, some studies have used an alcohol screening tool such as CAGE (a short and simple questionnaire about drinking habits) alongside cognitive impairment tests such as the Cognitive Ability Screening Instrument. The Mini Mental State Examination (MMSE) is the most commonly used test for complaints of memory problems or where a diagnosis of dementia is being considered. This has also been used alongside alcohol screening tools to investigate the relationship between dementia

and alcohol in various research projects.

Mental Health in Scotland: Closing the Gaps – Making a Difference: Commitment 13 (2007) published by an Advisory Group set up by the Scottish Executive recommends the use of a checklist developed by the Scottish Association for Mental Health and arbias Ltd (*Looking Forward: Recovering from Alcohol Related Brain Damage, a practical guide to working with people with ARBD, 2006*) as a helpful aid for frontline workers in identifying possible indicators of ARBI. The document further notes that the checklist and brief assessment tools such as MMSE can be of value in making an ARBI assessment but are not diagnostic tools for ARBI. Should the checklist and brief assessment tools indicate that a more complete assessment is required a number of standardised assessments have been identified by the Advisory Group which can be used by specialist clinical psychologists and neuropsychologists.

28. *Mental Health in Scotland: Closing the Gaps – Making a Difference: Commitment 13, Part 9, The Scottish Government, 2007*

These standardised assessments are listed as:

- WAIS111 - to assess overall profile (eliminate other problems)
- WTAR - to identify previous predicted level of functioning for comparative purposes
- Rey Auditory Verbal Learning Test - a list learning test which provides useful information re individual's capacity to learn. Useful for care planning.
- The Delis-Kaplan Executive Function System Subtests - can be used independently to assess executive functioning.
- Wechsler Memory Scale to assess different aspects of memory.²⁹

Jacques and Anderson (2002) suggested a standard approach to assessment for people in long-term care in hospital, care homes and supported accommodation. The view of those reporting is that initial diagnosis would be better confirmed by the coordinated use of a range of physical and cognitive function tests as well as subjective and objective assessment of alcohol use. Smith and Hillman (1990) argue that a full assessment of someone with ARBI is likely to take at least one year of abstinence and structured rehabilitative interventions.

3.4 Intervention

The range of factors involved in ARBI and the diversity of those affected by the condition presents many challenges in designing and delivering programmes of intervention, treatment and care. Literature shows that responding to the needs of people with ARBI requires a holistic approach involving health promotion and prevention, challenging stigma and discrimination, improving information, planning and delivering better services, training, service standards and more evaluation and research.

People with ARBI may have a range of problems, including depression, anxiety, dementia.³² This makes the planning and delivery of integrated care pathways an imperative but also presents major challenges in terms of designing the pathways and resourcing them. People with ARBI are also perceived to be high-risk patients because of the challenging behaviour they may exhibit

Again, literature shows that during the assessment and rehabilitation period, the individual will demonstrate social needs, but the primary focus will usually be on medical needs since rehabilitation usually takes place within a hospital setting.³⁰

A multi-disciplinary and inter-agency approach to assessment is therefore required, including:

- assessment of physical health and nutritional state
- psychiatric assessment
- neurophysiological assessment of attention, concentration, memory, perception, problem-solving, vocabulary and information-processing
- assessment of physical functioning
- assessment of social needs.³¹

Clearly, there are time and resource constraints involved in carrying out such a screening and assessment programme. There is evidence of integrated planning within health services in other areas, but the literature argues that there is a need for greater coordination and for standardised screening and assessment tools to be developed for ARBI.

and the vulnerability as a result of changes to cognitive function. This can lead to some people being placed in and remaining in age-inappropriate facilities. People may also be placed in inappropriate settings because of the difficulties in classifying the primary cause of their condition and, in some cases, the lack of dedicated resources to address their needs. The literature states however that treating people with ARBI as dementia cases to avoid accommodation problems is likely to result in further deterioration.

Evidence from the literature review shows that access to specialist alcohol assessment and treatment is extremely important. Improved outcomes depend on the individual having access to services including cognitive assessment especially neuropsychologists, occupational therapists, rehabilitation services and

32. Report of the Expert Group on Alcohol-Related Brain Damage: A Fuller Life, Scottish Executive, 2004

33. MacRae R, Cox S, Meeting the Needs of People with Alcohol Related Brain Damage: A Literature Review on the Existing and Recommended Service Provision and Models of Care, University of Stirling, 2003

general psychiatrists. Dedicated psychiatric beds for rehabilitation and continuing care are needed for the subgroup of people with ARBI who have major behavioural or psychiatric difficulties.

Those people who are already established with ARBI will require different treatments depending on the extent of their condition. The planning and delivery of health, social care and other interventions such as supported housing should, according to literature, be based on an holistic approach of screening, assessment, treatment, maintenance and review, with coordination along individual integrated pathways of care.

An issue highlighted in the literature is the importance of disseminating effective information to all relevant professionals and services providers. The literature also

suggests that those involved in commissioning, planning or providing services should recognise and provide for effective health promotion programmes and the provision of information and advice both to those who may be affected by ARBI and their carers.

A recurring theme throughout the literature is the importance of coordination and the need for those with ARBI to abstain from drinking or undergo managed alcohol withdrawal. However, during interviews conducted as part of the research for this report, it was highlighted that in some cases (the third and fourth quarters of people with ARBI referred to earlier) where people are unlikely to make a significant recovery, the emphasis should be on caring for people in places of safety with the management of their alcohol intake.

3.4.1 Alcohol Detoxification

The literature review highlights the importance of effective detoxification services to allow complete diagnosis and also to halt the progress of Korsakoff-Wernicke syndrome.

Detoxification can be provided through inpatient treatment or medically-supported community-based treatment and may often involve pharmacotherapeutic treatment. Inpatient treatment should be a planned for process wherever possible to increase the chance for completion of detoxification and maintenance of abstinence. Detox for those diagnosed with ARBI is likely to be through inpatient treatment given the difficulties in cognitive capacity that a person with ARBI may have.

The rationale for using medication as part of alcohol withdrawal is to provide relief from symptoms, to prevent serious complications of withdrawal and to achieve this using the minimum amount of medication. In order not to under or over-prescribe, 'symptom-triggered' prescribing is recommended for in-patient alcohol detoxification (Mayo-Smith, 1997). This involves the use of a standardised alcohol withdrawal scale to direct the administration of medication.

According to Trathen (2006) cited on DryOutNow.com the drug of choice for withdrawal is chlordiazepoxide (Librium). The site notes that a course of thiamine (Pabrinex) should be given over the first several days of detoxification to prevent against the development of Wernicke's Encephalopathy and chronic memory deficits. The process of detoxification can precipitate acute loss of thiamine (Vitamin B1) stores in people who are already chronically thiamine deficient and it is recommended that thiamine is given through intramuscular or intravenous routes in order to be effective.

Trathen (2006)³⁴ further notes that a presumptive diagnosis of Wernicke's Encephalopathy should be made if any of the following occur during detoxification: ataxia, confusion, memory disturbance, hypothermia, hypotension, ophthalmoplegia (paralysis of one or more muscles controlling eye movement) or nystagmus (involuntary eye movement), coma or unconsciousness. Trathen states that this represents a medical emergency and should result in immediate transfer to hospital, and treatment with high dose Pabrinex.

34. Trathen, B., Alcohol Guidelines, 2006, ISBN 0-9545164-0-0, cited on www.dryoutnow.com

For a home-based detox it is recommended that a nurse from the local addiction team acts as the observer and arranges for the GP to administer the Pabrinex in the surgery on days one to three of the detoxification and for the dispensing of chlordiazepoxide (Librium). Trathen also highlights that home detoxification should only be commenced if there is a supportive spouse or family member or friend who is willing to remain continuously with the individual for a minimum of 72 hours and for the majority of the rest of the week.

The Report of the HSE Working Group on Residential Treatment & Rehabilitation (Substance Abuse) (2007) noted that in the border corridor (counties Donegal, Leitrim, Sligo, Cavan, Monaghan and Louth) there are:

- No stabilisation services
- No community-based residential detox units
- No medical detoxification units.

The report notes that people who receive more than 90 days inpatient or outpatient treatment do better than those receiving a shorter period of care and at least 28 days in an inpatient or short-stay rehabilitation programme has been associated with the greatest chance of abstinence

With regard to alcohol misusers, the report cites that a number of studies have shown a significantly better outcome for residential services over non-residential services and that residential treatment is of greater benefit for those with more severe alcohol problems or with a dual diagnosis.

The report concludes that there are inadequate levels of residential services in the Republic of Ireland and in particular detoxification services and recommends that there should be 15 alcohol detoxification beds for each of the four HSE administrative regions together with six inpatient unit beds for detoxification and stabilisation of illicit drugs users in the HSE West region.

3.4.2 Service Response

Essential elements of an effective service response

- Crisis response
- Detoxification
- Managed alcohol withdrawal
- Assessment, care management, care planning and coordination
- Nursing Home care
- Rehabilitation
- Post-rehabilitation support and Ongoing care, support and treatment
- Carer support for family and direct care staff

Sources: *A Fuller Life, 2004* and *Meeting the Needs of People with Alcohol-Related Brain Damage, 2003*,
Scottish Executive and Alcohol-Related Brain Damage: A report of the learning captured from Carenza Care in North Wales, CSIP/Alzheimer's Society ARBD Working Group, June 2007

There is emerging practice evidence that it is possible for some people with ARBI to sustain a relatively high level of independent living but this depends on a number of factors:

Pre-requisites to Independent Living

- User and carer empowerment
- Abstinence from alcohol or at a carefully managed harm reduction programme
- Consistent support from staff with understanding and knowledge of ARBI
- Developing or redeveloping skills in daily living, developing and maintaining routines
- Safe living environment
- Good diet and nutrition
- Meaningful daytime activity
- Support from family and friends
- Activity-based rehabilitation strategies to improve memory and other cognitive impairment.

Source: A Fuller Life, 2004 and Meeting the Needs of People with Alcohol-Related Brain Damage, 2003, Scottish Executive

The literature further shows that the role of the specialist worker or case manager improves coordination and outcomes for individuals. Such an approach facilitates joint assessment, avoids duplication of effort and resources and facilitates 'local flags' in service providers' information systems (especially general practice) to highlight the multi-faceted care required for people with ARBI.

Additionally, effective monitoring and review are crucial because recovery and rehabilitation of people with ARBI will probably be long-term. The commonly-accepted view is that such monitoring and review should continue for a period of between one and two years from detoxification (Smith and Hillman, 1990, Bruce and Ritson, 1998, Jakes and Stevenson, 2000).³⁵

Research in Meeting the Needs of People with Alcohol Related Brain Damage: A Literature Review on the Existing and Recommended Service Provision and Models of Care (2003) concurs with the above, establishing that models of care and examples of good practice tend to have particular features:

- A focus on augmenting existing service provision by providing and/or facilitating an integrated response to early diagnosis and assessment
- Joint working to coordinate service provision, forward and contingency planning in care plans to help prevent admission and give support in discharge
- An identified lead practitioner to coordinate referrals and help navigate the person through their care pathway.

35. Report of the Expert Group on Alcohol-Related Brain Damage: A Fuller Life, Scottish Executive, 2004

3.5 Acquired Brain Injury

Acquired Brain Injury (ABI) is primarily considered to be a traumatic brain injury (an injury resulting from trauma to the head and its direct consequences). This is considered by many of those working in brain injury teams to be distinct from ARBI which is considered a non-traumatic brain injury. From discussions with health professionals during research for this report there further appears to be uncertainty as to whether Korsakoffs-Wernicke's is considered a mental health issue rather than a brain injury issue (since the condition of Korsakoffs-Wernicke's can become progressively worse, unlike an ABI) and there does not seem to be any clear consensus on this point. Some of the health professionals interviewed as part of the research for this report considered that ARBI should be treated as other types of brain injury and ABI strategies may therefore be relevant.

Whilst distinct from ARBI, many ABIs also involve alcohol. The *Phillips Report: National Report on Traumatic Brain Injury in the Republic of Ireland 2008* conducted by the Traumatic Brian Injury Research Group notes that alcohol was reported for one in four of the traumatic brain injuries in Ireland, that four in every five assaults involved alcohol and that alcohol was associated with a greater incidence of severe injury. The report noted however that there was inadequate recording of alcohol ingestion in 60% of medical notes.

In terms of treatment, the *Phillips Report* (2008) highlights that the Royal College of Surgeons in England and the 2007 NICE guidelines on the management of head injury recommend that all patients presenting with a severe brain injury be treated in a neurosurgical centre, whilst in Ireland 41% of patients with a severe traumatic brain injury are treated in a specialised unit.³⁶ The report notes that the lack of specialised facilities in Ireland has been reported by the Neurological Alliance of Ireland. The report recommends the provision of the following services for traumatic brain injuries:

- Emergency department: 24 hour CT access; scans performed and reported within 60 minutes
- Inter-hospital transfers: a poly-trauma patient should only be transferred when haemodynamically stable
- Provision of a 24 hour National Retrieval Service for critically ill patients

36. *Phillips Report: National Report on Traumatic Brain Injury in the Republic of Ireland 2008*, Traumatic Brain Injury Research Group, 2008

37. ABI Ireland is a community and voluntary organisation (formerly the Peter Bradley Foundation) that provides a range of services for people with ABI

- Neurosurgical management: provision of sufficient neuro-critical care facilities in Ireland
- Performance assessment: development of a national trauma registry.

With regards to alcohol as a significant contributing factor in traumatic brain injuries, the *Phillips Report* (2008) recommends that alcohol awareness strategies must highlight to the public the increased risk of serious injury associated with alcohol use. The report also notes that data is not currently collected in an organised way across Ireland and recommends that information collection needs to be part of an organised, cohesive system of audit which records information from all relevant services.

In terms of ABI policy in the Republic of Ireland, the Acquired Brain Injury Ireland website states that current health policy in Ireland does not recognise people with ABI as a distinctive group and that the organisation's experience of current services shows significant gaps in the provision of appropriate community support services for people with ABI or people with ABI being inappropriately responded to (such as placing individuals with ABI in residential institutions for older people and in acute hospitals).

In Northern Ireland the Department for Health, Social Services and Public Safety (DHSSPS) has recently published the *Acquired Brain Injury (ABI) Action Plan 2009/10-2010/11*. The Action Plan concentrates on four areas:

- Service redesign
- Quality improvement
- Improved support for individuals, carers and families
- Effective engagement and partnership working.

The Action Plan sets out two generic care pathways for further development for mild acquired brain injury and moderate to severe acquired brain injury (see Appendix A).

In addition, actions under the Plan will be coordinated through the Regional ABI Implementation Group in Northern Ireland.

3.6 Examples of Good Practice

The issues highlighted by the literature present many challenges to those who plan and commission services. The areas of ambiguity between where people with ARBI would best fit in terms of service provision have resulted in what appears to be an absence of consideration of ARBI as a discrete issue in the policies or strategies in both the Republic of Ireland and Northern Ireland.

As part of our literature review, we sought to identify projects or facilities demonstrating good practice in providing services specifically for people with ARBI. We did not find any within the Republic of Ireland or Northern Ireland, but note that a limiting factor could have been the reporting timeframe and further work may be required to fully establish the situation with the Republic of Ireland and Northern Ireland.

There are, however, examples of good practice in Scotland, Wales, England and Australia cited in the literature and gathered from desktop research, including:

SCOTLAND

- Inverclyde Alcohol Services (IAS) – part of Inverclyde Social Work and Housing Services, IAS provides care management for people with alcohol problems, about 20% of whom are people with ARBI. IAS links with local projects to provide a comprehensive care package and also links with the Community Mental Health Team and local NHS Trust. The staff do utilize a specific assessment tool for ARBI but it is usually recognised during the initial assessment
- Alzheimer Scotland - Action on Dementia Glasgow Younger Persons' Project – the project runs day care and home care services used by people with ARBI. Home support workers help people with ARBI to undertake courses to help regain life skills. The service also tries to match the age of the person with ARBI to the support worker. Most people the project works with live in the community but the service has also provided home support and day care in nursing homes for people with ARBI

- Diff'rently the Same Project – run by Turning Point Scotland in Glasgow the project provides day opportunities for people under 65 with dementia and includes people with ARBI. Day opportunities provide support with education, leisure and education. Support workers also work with people with ARBI living in care homes, who are often younger than the other residents and benefit from undertaking community activities
- Penumbra – provides a range of services for people with mental health problems across Scotland including housing and tenancy support services. In Edinburgh and Aberdeen there are specialist services for people with ARBI
- Loretto Housing – provides supported accommodation for four people with ARBI within flats in Glasgow
- Langcraigs residential home – based in Dumbarton, this home has a six-bed specialist unit for people with Korsakoff's
- Scottish Association for Mental Health (SAMH) – provides a number of services for people with ARBI including a care home for eight people with ARBI in Glasgow, care at home for people with ARBI in Inverclyde and housing support for six people with ARBI in Glasgow
- Gryffe Unit at Ravenscraig Hospital in Greenock – the unit provides in-patient and day-patient detoxification and rehabilitation for individuals with alcohol dependence. For people with ARBI and marked cognitive impairment an in-patient detoxification followed by a period of in-patient rehabilitation lasting up to 8 weeks is offered. The unit works closely with IAS so is able to provide a multi-agency approach through singled shared assessment

WALES

- Arbennig Unit in Colwyn Bay – the unit has 12 beds in six-bedded units for people under 65 who have ARBI. The unit offers a residential programme for assessment and rehabilitation lasting for up to two years and staff provide counselling, social care and physical rehabilitation. There is a focus on life skills to enable individuals to return to community or to reach the optimum level of recovery. The unit also has six flats within the same building where people with ARBI can live during rehabilitation

ENGLAND

- KorCare at Scope 2000 – this is a privately-owned registered care home in Devon caring for people with mental disorders or dual diagnosis and specialising in people with Korsakoff's. The home is registered for 26 residents and around 75% are people with ARBI. A range of therapeutic, recreational, social, cultural activities and facilities are available. They also offer guidance to carers and supporting people at home

AUSTRALIA

- ABI/AOD Clinical Consultants – Nine ABI/AOD (Acquired Brain Impairment/Alcohol and Other Drugs) Clinical Consultant positions were established in the region of Victoria, Australia. The primary role of the ABI/AOD Clinical Consultants is:

1. to identify individuals with ABI already in the drug treatment system
2. to facilitate access for clients with ABI in need of treatment
3. to keep clients with ABI in the service system by introducing appropriate models of treatment to AOD clinicians
4. to gauge the number of clients with ABIs receiving treatment in the AOD sector
5. to determine the resources needed to facilitate treatment of this client group.

The ABI/AOD Clinical Consultant engages in:

1. capacity building – building networks and links
2. direct treatment – providing counselling and coordination
3. secondary consultation – providing advice and support to other practitioners
4. information and education – providing informal and formal training sessions.

An evaluation by the Department of Human Services (2008) noted that the role of ABI/AOD Clinical Consultant has resulted in positive outcomes including:

1. increased interaction between the ABI and AOD sectors
 2. enhanced referral processes leading to an increase in referral rates
 3. increased service knowledge
 4. increased awareness of ABI/AOD issues
 5. individuals being linked in to appropriate services³⁸
- arbias Ltd – provides specialist services in alcohol and other substance-related brain impairment nationally in Australia and particularly the region of Victoria. The services provided by arbias include neuropsychological assessment, case management, housing, lifestyle support, information and training and workforce training and development
 - The Wicking Project – established by Wintringham Services in Melbourne, Australia, providing services to older homeless men and women. The Wicking Project ran as an 18-month trial from 2008 to 2009. The aim was to develop a psychosocial model of long-term residential care in a community house for four older people with ARBI, providing individualised and specialised care, support and behaviour management strategies. An evaluation of the project has not been published to date.

38. Famularo-Doyle J, Campbell R and Brick J, ABI/AOD Clinical Consultants: Innovative Practice Between Service Sectors and Koymon T, The Benefits of the ABI/AOD Clinical Consultants Role. A Solution to Bridging Gaps in Rural and Remote Areas: A Gippsland Perspective. Both presentations are on www.abis.org.au

Key Points on ARBI

Prevalence

- Information on the incidence and prevalence of ARBI nationally and internationally is difficult to establish because of the differences in systems for capturing and recording information. However, there are signs of an overall increase in the number of people with ARBI
- There is evidence of a concentration of ARBI in areas of high socio-economic deprivation
- Policy makers and planners are unclear where ARBI fits within different departmental and financial systems and what service models are effective or what outcome measures are appropriate
- There is evidence that the condition is under-diagnosed
- Identifying the population involved is difficult
- Research suggests that ARBI accounts for 10% of the dementia population (Lishman, 1990) and for 12.5% of dementias of people under 65 (Harvey et al, 1998)

Assessment and Diagnosis

- The complexity of ARBI makes assessment of the condition difficult.
- Heavy drinkers are not likely to know that they are acquiring problems due to impairment of insight and awareness and are therefore not likely to turn up in the health system until they become sick, although cognitive decline is likely to already have begun.
- The point of entry to services for people with ARBI can be largely a matter of chance.
- ARBI, by its nature, requires interventions at all levels of the four-tier model of intervention.
- There is no standard screening tool for ARBI.
- It is not possible to have an accurate assessment of ARBI unless individuals abstain from alcohol for a significant period of time – from three to six months.
- It is important that assessment is ongoing, and many of the literature sources researched would argue that this is best facilitated through the model of a specialist worker.
- A multi-disciplinary and inter-agency approach to assessment is required.

Intervention

- Half of those with an ARBI can make a complete or significant recovery, whilst a quarter will make no recovery at all (A Fuller Life, 2004).
- People with ARBI may often be placed in inappropriate care or accommodation settings.
- The treatment and rehabilitation required will depend on the severity of the ARBI.
- Improved outcomes depend on the individual having access to services including cognitive assessment especially neuropsychologists, occupational therapists, rehabilitation services and general psychiatrists.
- The essential elements of a service response are:
 1. Crisis response
 2. Detoxification
 3. Managed alcohol withdrawal
 4. Assessment, care management, care planning and coordination
 5. Nursing Home care
 6. Rehabilitation
 7. Post-rehabilitation support and Ongoing care, support and treatment
 8. Carer support for family and direct care staff

Key Points on ARBI

- Models of care and examples of good practice tend to have particular features:
 1. A focus on augmenting existing service provision by providing and/or facilitating an integrated response to early diagnosis and assessment
 2. Joint working to coordinate service provision, forward and contingency planning in care plans to help prevent admission and give support in discharge
 3. An identified lead practitioner to coordinate referrals and help navigate the person through their care pathway.

General conclusions

- ARBI is a complex condition. It may be present with a number of other conditions such as depression and anxiety and a person at the more acute end of the ARBI spectrum will require very different care and treatment than a person diagnosed at an earlier stage of the condition.
- Policy makers and planners are unclear where ARBI fits within different departmental and financial systems and what service models are effective or what outcome measures are appropriate.
- Sharing information between agencies is crucial but clear diagnoses and the availability of and access to integrated records is some way off.
- It is recognised that there is a need for better coordination of screening, assessment, treatment and care, but there is a challenge in terms of identifying the population with ARBI and in tailoring services to meet their needs.
- Unless and until there is greater clarity in terms of incidence and prevalence and diagnoses there is a continual risk of people with ARBI being placed in inappropriate care settings or missing out on care altogether.
- There are a number of examples of models of care from Scotland and Australia that range from supported accommodation provision in the not-for-profit and private sectors to case worker models in the public health services.

4. Policy Approach to ARBI

This section looks at the strategic context and policy drivers for the treatment and care of those with ARBI.

4.1 Overview

Within the Republic of Ireland and Northern Ireland there are no specific strategies or government plans directed at ARBI. Likewise, in the Republic of Ireland current health policy does not appear to recognise people with ABI as a distinctive group.³⁹ This said, there are a number of policies which impact on brain injury, mental health and addictions within both jurisdictions (although none directly refer to ARBI):

REPUBLIC OF IRELAND

- National Substance Misuse Strategy 2009-2016, Department of Health and Children – the drugs policy element of this strategy has already been agreed and published under the National Drugs Strategy 2009-2016 and work is ongoing to develop policy in relation to alcohol for an overall Substance Misuse Strategy
- A Vision for Change: Report of the Expert Group on Mental Health Policy, 2006 – This report sets out a comprehensive model of mental health service provision, based on a person-centred and integrated multi-disciplinary approach to treating and caring those with a mental illness

4.2 International Policy Development on ARBI

Following the report *A Fuller Life* for the Scottish Executive in 2004, the Scottish Government published *Mental Health in Scotland: Closing the Gaps – Making a Difference: Commitment 13* in 2007. ARBI is featured distinctly within this policy document which states that:

- service commissioners should ensure awareness among services in their area of the risks of ARBI and that services dealing with high risk groups include ARBI prevention in their range of responses
- utilisation of the checklist developed by the Scottish Association for Mental Health and arbias (*Looking*

NORTHERN IRELAND

- New Strategic Direction for Alcohol and Drugs 2006 – 2011, DHSSPS – the strategy aims to develop a fully-integrated, inclusive and coordinated strategic direction for addressing alcohol and drug misuse at both a regional and local and community level
- Bamford Review of Mental Health and Learning Disability – Alcohol and Substance Misuse Report, 2005 – the report set out a number of recommendations covering a wide range of service planning, delivery and treatment across the range of providers in the four-tier model
- Acquired Brain Injury (ABI) Action Plan 2009/10-2010/11, DHSSPS (see section 3.5).

This lack of a specific policy driver that sets out clearly the provision for people with ARBI has a subsequent impact on the individual of ‘bouncing between services’ – a factor that was noted by some of the health professionals interviewed for this research (see section 5.3).

Forward: Recovering from Alcohol Related Brain Damage, a practical guide to working with people with ARBD, 2006 as a helpful aid for frontline workers in identifying possible indicators of ARBI

- access to specialist practitioners and facilities to enable full assessments and diagnosis of cognitive impairment
- utilisation of a number of standardised assessments by specialist clinical psychologists and neuropsychologists after a period of three-six weeks abstinence

39. http://www.abireland.ie/aboutABI_policy.html

- for many with mild ARBI the most important element of care will be to achieve prevention or relapse back into alcohol use and in these instances alcohol agencies should be the main providers of care
- care should be based on need, not age or causation
- the issues faced in providing care and treatment for those diagnosed with moderate to severe ARBI have much in common with those faced by people with Huntingdon's Disease, Acquired Brain Injury and Early Onset Dementia
- Contributors to the report suggested exploration of a model of a needs-based neuro-rehabilitation approach which would build on the evidence base examples of good practice in the statutory and voluntary sector.

In Australia, the Government has included assessment and treatment of ARBI within its *Guidelines for the Treatment of Alcohol Problems* (Department of Health and Ageing, 2009). The guidelines are aimed at a broad range of health professionals including health service planners. With regard to ARBI, the guidelines state that all heavy or chronic drinkers should be considered at risk of developing Wernicke's encephalopathy. The guidelines recommend that, since the cost is not significant (and giving that the health impacts of Wernicke's encephalopathy are high and that there may be a large number of undiagnosed people), thiamine treatment is given to all patients undergoing alcohol withdrawal or any heavy drinker displaying features of Wernicke's encephalopathy. The guidelines highlight the need for early treatment since delays in treatment may worsen the patient's prognosis.

5. Local Context – Incidence of ARBI

5.1 Methodology

This section presents the results of the data collection from both the HSE North West and WHSCT with regard to incidence of ARBI over the last five years.

The methodology followed with regard to the data collection was as follows:

- Agreement with the NWAF sub-group of the conditions covered by ARBI as follows:
 1. Cerebellar Atrophy
 2. Peripheral Neuropathy
 3. Hepatic Encephalopathy
 4. Frontal Lobe Dysfunction
 5. Wernicke's Encephalopathy
 6. Korsakoff's Amnesic Syndrome
- Agreement with the NWAF sub-group of the data sets we would aim to gather. The data sets were further agreed with the HIPE (Hospital Inpatient Enquiry) Coordinator in Letterkenny General Hospital and the Information Department within the WHSCT:
 - Admissions to acute hospitals with primary or secondary diagnosis of ARBI for the last five years (2004-2009) by:
 1. Gender
 2. Age band (under 16, 16-24 years, 25-34 years, 35-44 years, 45-54 years, 55-64 years, 65+)
 3. County/Council area of residence
 4. Destination on discharge
- Consideration of the ethical issues pertaining to this research both by us and within the HSE. Whilst we prepared a letter requesting approval from the ethics committees in each jurisdiction if required, both the HIPE Coordinator at Letterkenny General Hospital and the Information Department at the WHSCT considered that it was not necessary to seek full ethical approval since the information contained would be anonymised and would not contain identifiers.
- Determination of the ICD-10 codes relating to each condition. To determine the codes we met and liaised with the HIPE Coordinator in Letterkenny General Hospital, a Senior Information Officer in the Health

and Social Care Board, West (NI) and a Consultant in Public Health Medicine from the Public Health Agency (NI). The ICD-10 codes identified are as follows:

1. Cerebellar Atrophy – G31.2
 2. Peripheral Neuropathy – G62.1
 3. Hepatic Encephalopathy – G31.2 and K72.9.
- Note: K72 is hepatic failure not classified and includes encephalopathy so other non-specified causes will be included as well as alcohol-related. Hepatic Encephalopathy does not include alcohol cirrhosis of the liver which is recorded under K70.3
4. Frontal Lobe Dysfunction – G93.8 or F07.0
 5. Wernicke's Encephalopathy – E51.2
 6. Korsakoff's Amnesic Syndrome – F10.6

We have sought to qualify the exact ICD-10 codes for conditions where different ICD-10 codes were identified by different health staff but have been unable to resolve these questions during the timeframe. We recommend therefore that further work is undertaken to verify and quality assure the ICD-10 codes identified.

- There were a number of admissions from people aged under 24 during the period (seven in the HSE North West and six in the WHSCT). We note however that it is unlikely that these are due to an alcohol-related condition and recommend that further research is conducted to determine whether, for example, hepatic encephalopathy can be diagnosed without alcohol being a factor.
- Liaised with HIPE Coordinators at Letterkenny General Hospital and Sligo General Hospital and the Information Department at the Western Health and Social Care Trust to run the above reports. It should be noted that not all data was retrievable from the systems in each year (some old data was no longer in the systems whilst some more recent data was still being processed). It should be noted that each jurisdiction also records the information in different ways – the acute hospitals in Sligo and Letterkenny record information in calendar years whilst the WHSCT records the information by financial year.

The years for which we have obtained information are as follows:

1. HSE NW: 2005-2009
 2. Western Health and Social Care Trust: 1 April 2005 – 31 March 2009 (Tyrone County, Altnagelvin and Erne Hospitals). Whilst we were provided with information for the year 2009/10 for the Erne Hospital we have not included it within this report comparator information was not available for other acute hospitals
 - Liaised with staff in the Health Research Board to discuss available information
 - Meetings or telephone interviews with key staff including:
 1. Manager of Addictions Services, HSE (Donegal)
 2. Nurse Consultant in Alcohol Detoxification within Addictions Services, HSE (Donegal)
 3. Manager of Physical and Sensory Disability Services, HSE (Donegal)
 4. Clinical Director for Mental Health Services, HSE (Donegal)
 5. Consultant Psychologist, HSE (Donegal)
 6. Service Manager, Older People Services, HSE (Donegal)
 7. Director of Nursing, Mental Health, HSE (Sligo/Leitrim)
 8. Head of Addiction Services, HSE (Sligo/Leitrim)
 9. Addiction Counsellor, HSE (Sligo/Leitrim)
 10. Head of Mental Health, Specialist Services, WHSCT
 11. Manager of the Community Addiction Team (Northern Sector), WHSCT
 12. Manager of the Community Addiction Team (Southern Sector), WHSCT
 13. Consultant Psychologist, Community Brain Injury Services, WHSCT
 14. Consultant Older Age Psychiatrist, WHSCT
- Anecdotal information was also obtained from the Managers of Foyle Valley House and House in the Wells, supported accommodation facilities for men and women in Derry

5.2 Incidence

As stated previously, we obtained data from all the acute hospitals within the HSE North West and WHSCT areas. Before setting out and analysing this data in detail we note a number of limitations in the data:

- The data collected from Letterkenny and Sligo General Hospitals covers all the conditions listed and is not broken down by condition, whereas the data collected from the WHSCT has been broken down by condition
- The data provided notes the number of admissions rather than the number of individuals. One individual may therefore account for more than one admission
- There has been a recognition by health professionals (see section 5.2.3) that a high degree of under-reporting is likely due to difficulties in bringing people to a position where a diagnosis can be made, the complexities involved in making a diagnosis and the resources involved
- Data protocols may not record more than a certain number of diagnoses (eg four) – therefore, if a diagnosis of Korsakoff's for example is the fifth secondary diagnosis it will not be recorded in the system

- The data only relates to acute hospitals. There may be individuals in nursing homes or mental health facilities who have ARBI and these are not captured here
- These figures represent admissions for the eight conditions specified for ARBI for the purposes of this report. As highlighted by some health professionals we interviewed there are potentially other conditions such as alcohol-related dementia that are not included within this data collection – by focusing solely on the eight conditions the picture presented may under-report the wider issue of brain damage caused by alcohol and the potential need for services in these areas.

Taking the issue of under-reporting into consideration and in trying to calculate the potential population that may be affected by ARBI, a study conducted (albeit in 1990) (Lishman, 1990)⁴⁰ indicated that ARBI accounts for 10% of the total population with dementia and 12.5% of the dementias of those people under 65.

40. MacRae R, Cox S, Meeting the Needs of People with Alcohol Related Brain Damage: A Literature Review on the Existing and Recommended Service Provision and Models of Care, University of Stirling, 2003

Table 3:

shows the position in the HSE North West and WHSCT areas by applying those percentages.

Area	Number of People with Dementia	Estimated ARBIs (based on 10% of those with dementia)
HSE West – Donegal	1,471 people (2002)	147 people
HSE West – Sligo	638 people (2002)	63 people
HSE West – Leitrim	351 people (2002)	35 people
WHSCT	2,000 people aged 65 years and over (2005)	200 people

Source: *State of our Health, Western Investing for Health Partnership and Western Health and Social Services Board (November 2005)*

Source: O’Shea E., *Implementing Policy for Dementia Care in Ireland: The Time for Action is Now* (February 2007)

Assuming that the figures in the table above are a more accurate assessment of the prevalence of ARBI than the data presented in section 5.2, it is clear that the numbers of individuals remains relatively small as a percentage of the population. It should be noted however that, although the numbers may be small, the consequences and impacts on the individuals, their families and carers, and health services are very significant.

5.2.1 Health Service Executive – North West Area (Donegal, Sligo & Leitrim)

Table 4:

HSE NW – ARBI Admissions to Acute Hospital (2005-2009)

Year	Hospital	Total No of Admissions	Total
2005	Letterkenny General Sligo General	17 17	34
2006	Letterkenny General Sligo General	20 11	31
2007	Letterkenny General Sligo General	18 17	35
2008	Letterkenny General Sligo General	12 12	24
2009	Letterkenny General Sligo General	25 14	39
		Total	163

Source: HSE (Donegal) and HSE (Sligo/Leitrim)

Table 5:

HSE NW – Admissions to Psychiatric Units and Hospitals with a Diagnosis of Korsakoff's Amnesic Syndrome (F10.6) (2004-2008)

Year	County			Total
	Donegal	Sligo	Leitrim	
2004	0	0	0	0
2005	0	0	0	0
2006	1	1	0	2
2007	0	1	0	1
2008	0	1	0	1
Total	1	3	0	4

Source: Health Research Board

As can be seen from Table 4, the number of admissions to both Letterkenny and Sligo General Hospitals with conditions included in the ARBI spectrum has been relatively stable over the period:

- at its lowest point in 2006 Sligo General Hospital noted 11 admissions whilst its highest was the following year in 2007 with 17 admissions
- the lowest number of admissions recorded at Letterkenny General Hospital was in 2008 with 12 admission whilst the peak was in 2009 with 25 admissions
- the average number of admissions to acute hospitals in the HSE North West area over the five-year period with ARBI conditions was 32.6.

Admissions to psychiatric units and hospitals within the period 2004-2008 for people with a diagnosis of F10.6 (Korsakoff's Amnesic Syndrome) are small with only one admission in some years.

The average annual incidence of individuals treated for alcohol in the HSE North West area per 100,000 population is 771.9 (the highest level of incidence in the Republic of Ireland)⁴¹ In 2009 there were 1,493 treatment episodes by the addictions services in Donegal, Sligo and Leitrim.⁴² As a broad estimate and assuming that each ARBI admission is for one individual, ARBI admissions for 2009 (39 admissions) represent 2.6% of the individuals treated by the addiction services.

Over the period there was a small increase in the number of admissions of 14.7% (34 admissions in 2005 to 39 admissions in 2009). This being said, we note that there was a 100% increase in admissions for Letterkenny General from its lowest admissions rate in 2008 (12 admissions) to its highest rate in 2009 (25 admissions) although we are unable to determine which condition(s) this relates to without a breakdown in admissions by condition.

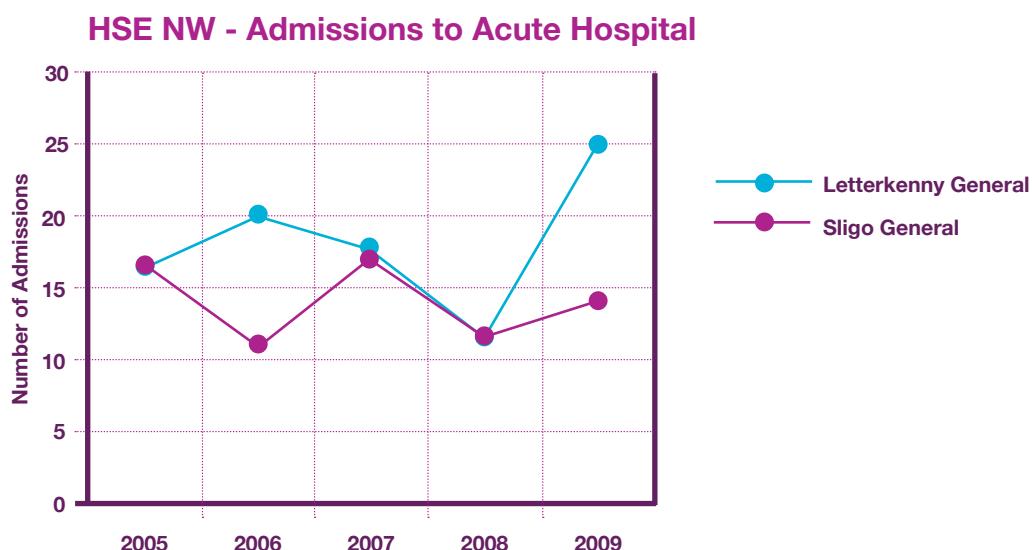
Accounting for the changes in numbers of admissions is difficult at this stage. It may be the case that an increase of seven admissions in a year may be linked to one or two individuals rather than seven separate individuals.

41. Health Research Board, Treated Problem Alcohol Use in Ireland, 2008

42. Source: returns made by Addictions Services to the Health Research Board

Figure 1:

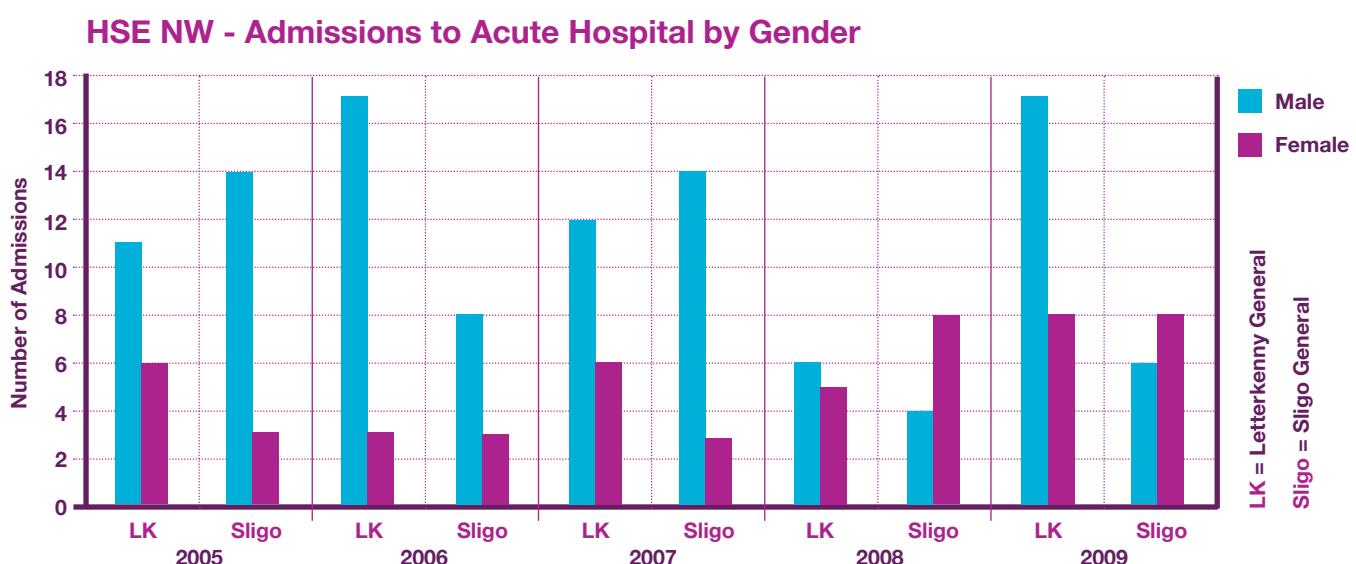
HSE NW – ARBI Admissions to Acute Hospital (2005-2009)



Source: HSE (Donegal) and HSE (Sligo/Leitrim)

Figure 2:

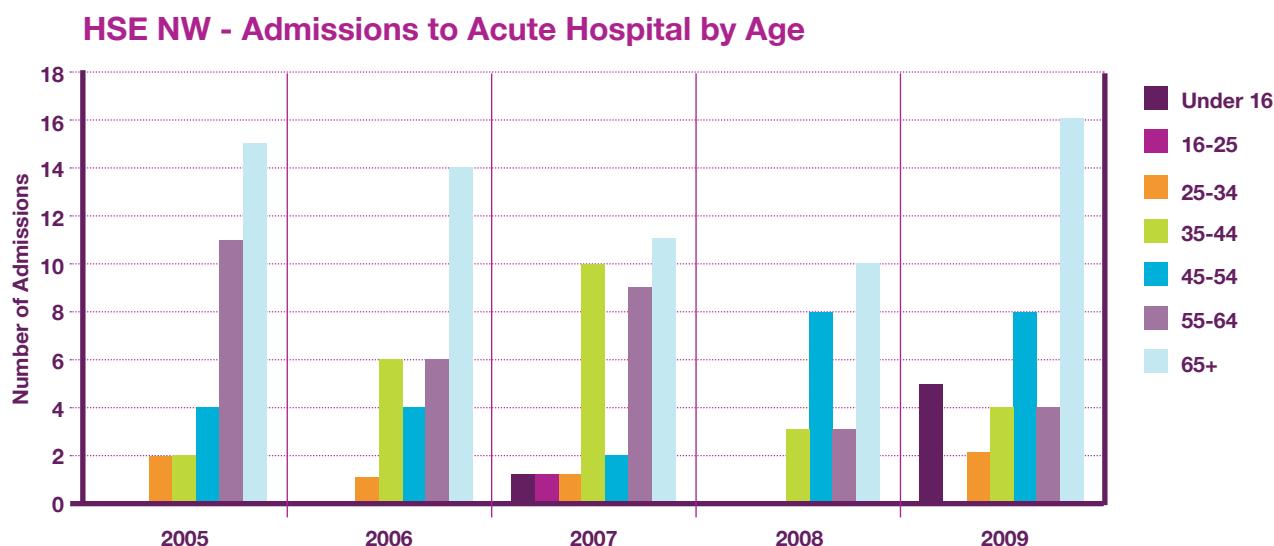
HSE NW – ARBI Admissions to Acute Hospital by Gender (2005-2009)



Source: HSE (Donegal) and HSE (Sligo/Leitrim)

Figure 3:

HSE NW – Potential ARBI Admissions to Acute Hospital by Age (2005-2009)

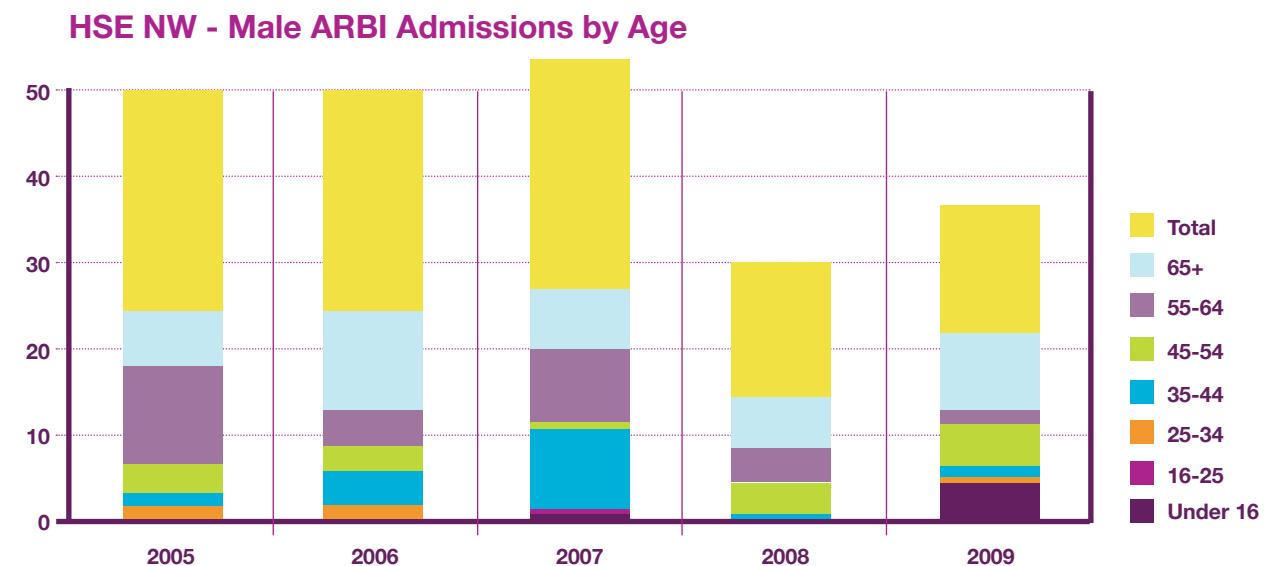


Source: HSE (Donegal) and HSE (Sligo/Leitrim)

As can be seen from the above charts, the profile of people admitted to acute hospital in the HSE North West is predominantly male, aged over 55, with Letterkenny General Hospital admitting a higher proportion of people coded with one of the conditions covered by ARBI. It is noteworthy however that the number of people admitted and for whom a diagnosis of one of the ARBI conditions is made within the 45-54 year age range has doubled from 2005 levels and, in line with research from the literature review, indicates that the age profile may be getting younger or that people are presenting earlier. This said, we note that it is unlikely that the admissions of people aged under 34 during the period are due to an alcohol-related condition and recommend that further research is conducted to determine whether, for example, hepatic encephalopathy can be diagnosed without alcohol being a factor. Further research to breakdown the admissions by condition is also required to determine the age profile of admissions by condition.

Figure 4:

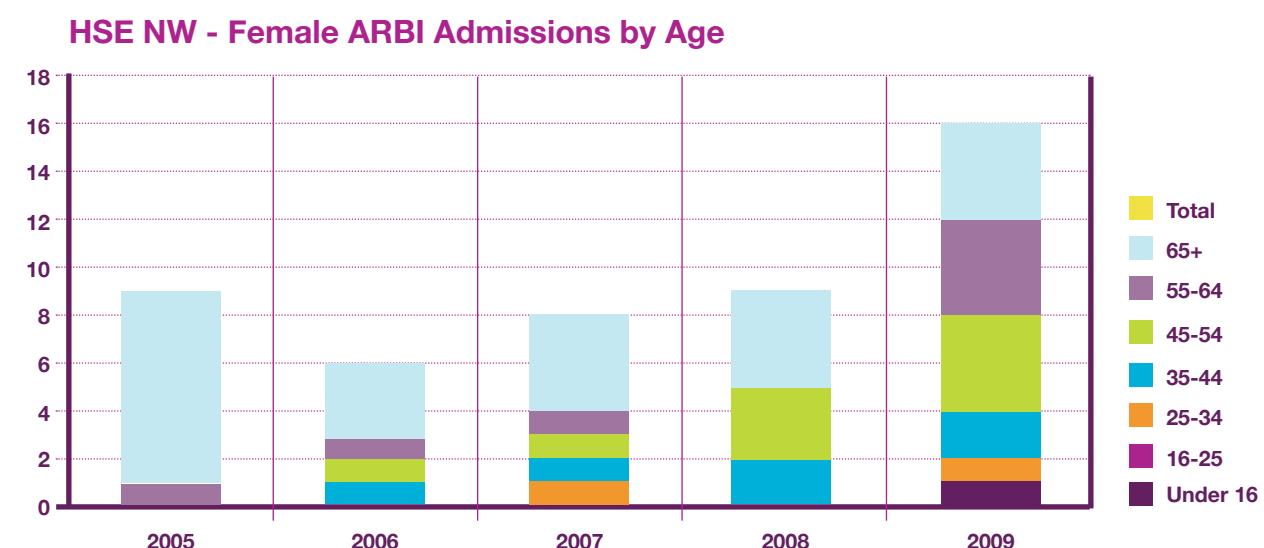
HSE NW – Male ARBI Admissions to Hospital by Age (2005 – 2009)



Source: HSE (Donegal) and HSE (Sligo/Leitrim)

Figure 5:

HSE NW – Female ARBI Admissions to Hospital by Age (2005 – 2009)



Source: HSE (Donegal) and HSE (Sligo/Leitrim)

In line with the profile outlined in the literature review, 61.7% of male admissions to acute hospitals in the HSE North West area over the period were aged over 55 and 62.5% of female admissions to hospitals in the HSE North West area over the period were aged over 55.

Table 6:

HSE NW – ARBI Admissions to Acute Hospitals by Gender and Age Type (2005-2009)

Year	Hospital	No of Males	No of Females	Age band						
				Under 16	16-24	25-34	35-44	45-54	55-64	65+
2005	Letterkenny General	11	6	0	0	2	0	2	5	8
	Sligo General	14	3	0	0	0	2	2	6	7
2006	Letterkenny General	17	3	0	0	1	2	3	2	12
	Sligo General	8	3	0	0	0	4	1	4	2
2007	Letterkenny General	12	6	1	1	1	0	1	6	8
	Sligo General	15	2	0	0	0	10	1	3	3
2008	Letterkenny General	7	5	0	0	0	1	5	0	6
	Sligo General	4	8	0	0	0	2	3	3	4
2009	Letterkenny General	17	8	4	0	1	3	6	2	9
	Sligo General	6	8	1	0	1	1	2	3	5
Total		111	52	6	1	6	25	26	34	64

Source: HSE (Donegal) and HSE (Sligo/Leitrim)

Note that it is unlikely that the admissions of people aged under 34 during the period are due to an alcohol-related condition and we recommend that further research is needed to determine the exact reason for these referrals.

Table 7:

HSE NW – ARBI Admissions to Acute Hospital by County of Residence (2005-2009)

Year	Hospital	Donegal	Sligo	Leitrim	Roscommon
2005	Letterkenny General	17	0	0	0
	Sligo General	3	11	2	1
2006	Letterkenny General	20	0	0	0
	Sligo General	1	9	1	0
2007	Letterkenny General	18	0	0	0
	Sligo General	3	11	2	1
2008	Letterkenny General	12	0	0	0
	Sligo General	2	9	1	0
2009	Letterkenny General	25	0	0	0
	Sligo General	3	6	3	2
Total		104	46	9	4

Source: HSE (Donegal) and HSE (Sligo/Leitrim)

All those admitted to Letterkenny General Hospital with an ARBI coding resided in Donegal and the majority of those admitted to Sligo General Hospital with an ARBI coding resided in Sligo.

Table 8:

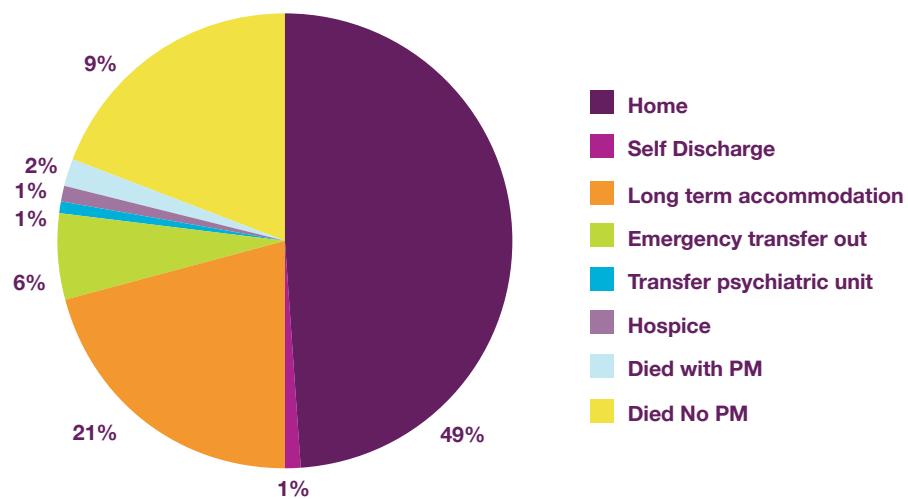
HSE NW – ARBI Admissions to Acute Hospital by Destination on Discharge (2005-2009)

Year	Hospital	Destination on Discharge							
		Home	Self-Discharge	Long term accommodation	Emergency transfer out	Transfer to psychiatric unit	Hospice	Died with PM	Died No PM
2005	Letterkenny General	10	-	-	-	-	-	-	2
	Sligo General	6	-	7	1	-	-	1	2
2006	Letterkenny General	7	1	4	-	-	-	-	3
	Sligo General	5	-	4	1	-	-	-	1
2007	Letterkenny General	8	-	3	1	-	-	-	3
	Sligo General	7	-	6	3	-	-	-	1
2008	Letterkenny General	7	-	-	-	-	-	-	3
	Sligo General	4	-	3	2	1	1	-	1
2009	Letterkenny General	8	-	2	-	-	1	1	9
	Sligo General	9	-	1	-	-	-	1	3
Total		71	1	30	8	1	2	3	28

The majority of those discharged from Letterkenny and Sligo General Hospitals with an ARBI coding returned home (49%) or to long-term accommodation (21%) or died in hospital (21%).

Figure 6:

HSE NW – Total Destination on Discharge (2005-2009)

HSE NW - Destination on Discharge (2005-2009)

Source: HSE (Donegal) and HSE (Sligo/Leitrim)

5.2.2 Western Health and Social Care Trust**Table 9:**

WHSCT – ARBI Admissions to Acute Hospital (2005/06-2008/09)

Year	Hospital	Total No of Admissions	Total
2005/06	Altnagelvin Tyrone County Erne	29 2 8	39
2006/07	Altnagelvin Tyrone County Erne	17 12 4	33
2007/08	Altnagelvin Tyrone County Erne	22 6 6	34
2008/09	Altnagelvin Tyrone County Erne	26 6 13	45
		Total	151

Source: WHSCT

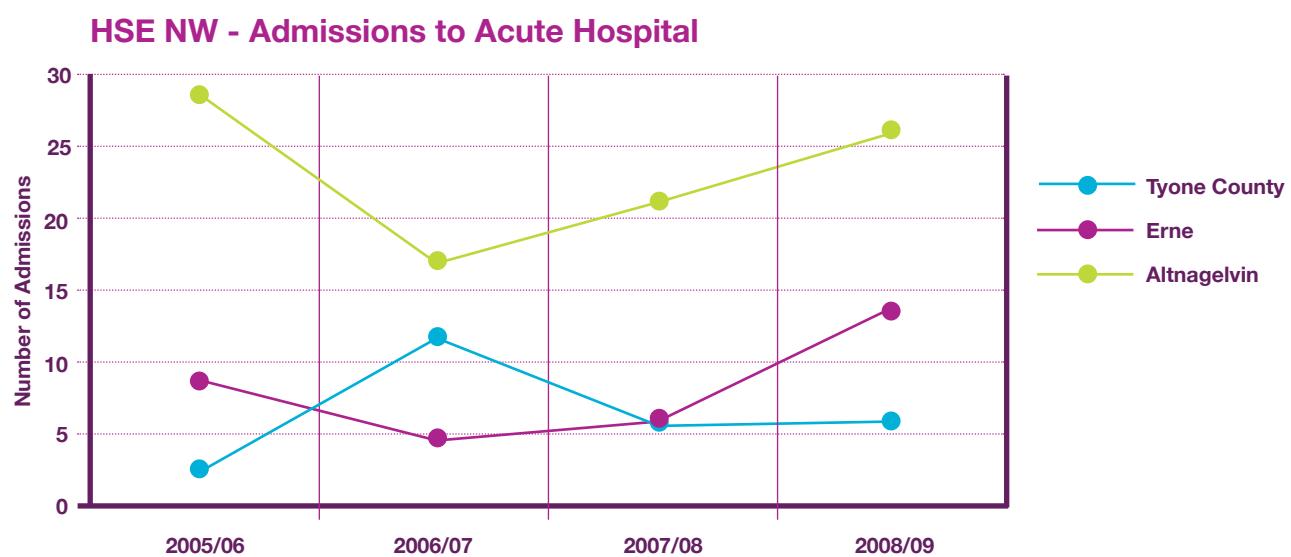
As for the HSE North West area, the number of admissions to all three acute hospitals in the WHSCT area with conditions included in the ARBI spectrum has been relatively stable:

- Altnagelvin Hospital records the highest number of admissions in the WHSCT over the period, perhaps reflecting its sub-regional status
- The number of admissions dropped 15% to 33 admissions from 2005/2006 to 2006/07 – the lowest number of admissions within the period
- The number of admissions rose significantly (36%) from its lowest point in 2006/07 to its highest point in 2008/09
- The average number of admissions to acute hospitals in the WHSCT area over the four-year period with ARBI conditions was 37.7.

There were 483 individuals in treatment for alcohol in the WHSCT on 1 March 2010.⁴³ As a broad estimate of ARBI as a percentage of the number of people in treatment (assuming that each ARBI admission is for one individual), ARBI admissions for 2008/09 (45 admissions) represent 9.3% of the individuals in treatment for alcohol in 2010.

As with the results for the HSE North West, accounting for the changes in numbers of admissions is difficult without a detailed examination of individual medical history or an understanding of the number of individuals as opposed to the number of admissions.

Figure 7:
WHSCT – ARBI Admissions to Acute Hospitals (2005/06 – 2008/09)



Source: WHSCT

43. Census of Drug and Alcohol Treatment Services in Northern Ireland: 1 March 2010,
Northern Ireland Statistics and Research Agency and the Department of Health, Social Services and Public Safety

Figure 8:

WHSCT – ARBI Admissions by Condition (2005/06 - 2008/09)

WHSCT - Admissions by Condition

Source: WHSCT

As can be seen from the above charts, there were no admissions during the period with a diagnosis of Wernicke's Encephalopathy. Although research shows that Korsakoff's Amnesic Syndrome may occur without Wernicke's preceding, it can often result from untreated Wernicke's – the absence therefore of any diagnoses of Wernicke's over the five-year period is perhaps somewhat unusual and we would suggest that further research would be required to determine whether this is due to under-reporting of Wernicke's or difficulties in diagnosing or coding the condition.

The largest number of admissions were for a primary or secondary diagnosis of Hepatic Encephalopathy (77 admissions over the period), followed by Cerebellar Atrophy (28 admissions), Peripheral Neuropathy (16 admissions), Frontal Lobe Dysfunction (16 admissions) and Korsakoff's Amnesic Syndrome (13 admissions).

Table 10:

WHSCT – ARBI Admissions by Condition and Hospital (2005/06 – 2008/09)

Year	Hospital	Total No of Admissions	Condition Type					
			Cerebellar Atrophy	Peripheral Neuropathy	Hepatic Encephalopathy	Frontal Lobe Dysfunction	Wernicke's Encephalopathy	Korsakoff's Amnesic Syndrome
2005/06	Tyrone County	2	-	-	2	-	-	-
	Erne	8	-	-	7	1	-	-
	Altnagelvin	29	4	-	18	3	-	2
2006/07	Tyrone County	12	6	-	4	-	-	2
	Erne	4	-	1	3	-	-	-
	Altnagelvin	17	4	6	4	2	-	1
2007/08	Tyrone County	6	-	1	4	-	-	1
	Erne	6	-	-	5	-	-	1
	Altnagelvin	22	3	4	14	2	-	-
2008/09	Tyrone County	6	1	-	3	2	-	-
	Erne	13	2	-	6	2	-	3
	Altnagelvin	26	8	4	7	4	-	3
Total		151	28	16	77	16	0	13

Source: WHSCT

Table 11:

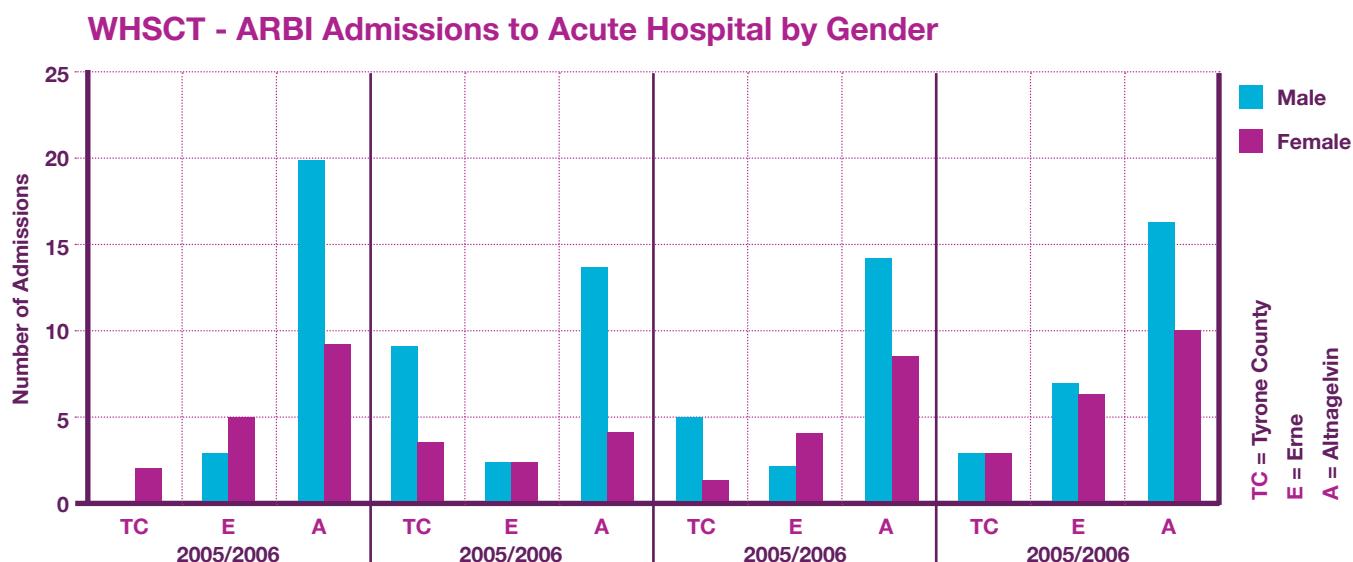
WHSCT – ARBI Admissions to Acute Hospital by Gender and Age Type (2005/06 – 2008/09)

Year	Hospital	No of Males	No of Females	Age band						
				Under 16	16-24	25-34	35-44	45-54	55-64	65+
2005/06	Tyrone County	-	2	-	-	-	1	-	-	1
	Erne	3	5	1	-	1	-	-	-	6
	Altnagelvin	20	9	-	1	-	2	10	6	10
2006/07	Tyrone County	9	3	-	-	-	-	1	8	3
	Erne	2	2	-	-	-	-	-	3	1
	Altnagelvin	13	4	2	-	1	2	5	3	4
2007/08	Tyrone County	5	1	-	-	-	2	1	3	-
	Erne	2	4	-	-	-	-	1	5	-
	Altnagelvin	14	8	-	1	2	5	7	3	4
2008/09	Tyrone County	3	3	-	-	-	-	4	1	1
	Erne	7	6	-	-	1	2	3	5	2
	Altnagelvin	16	10	1	-	2	6	2	7	8
Total		94	57	4	2	7	20	34	44	40

Source: WHSCT

Figure 9:

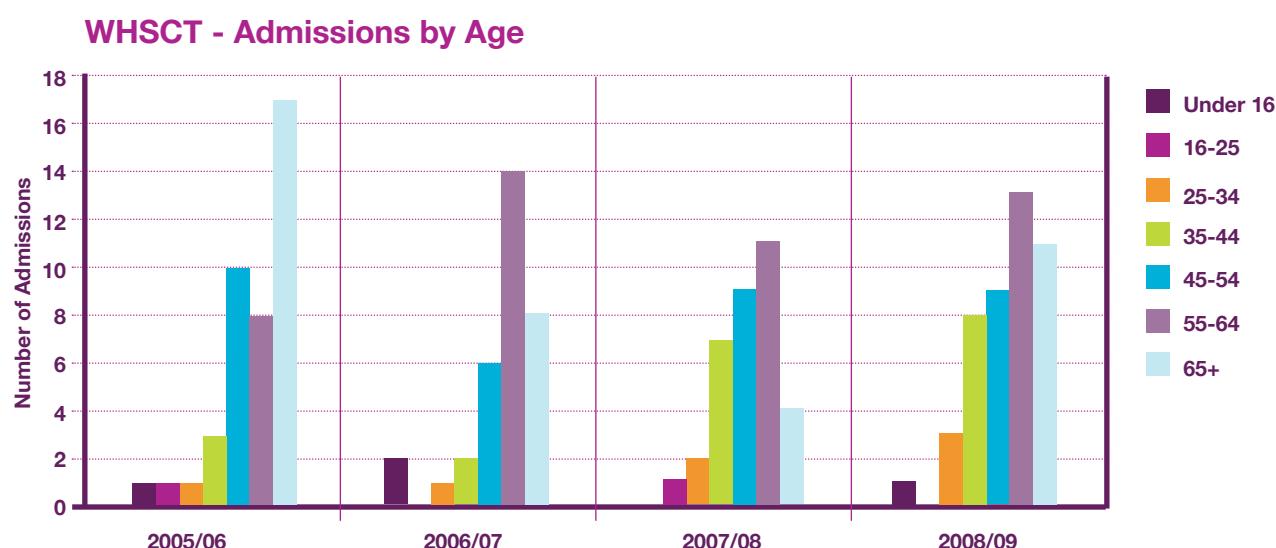
WHSCT – ARBI Admissions to Acute Hospital by Gender (2005/06 – 2008/09)



Source: WHSCT

Figure 10:

WHSCT – ARBI Admissions to Acute Hospital by Age (2005/06 – 2008/09)



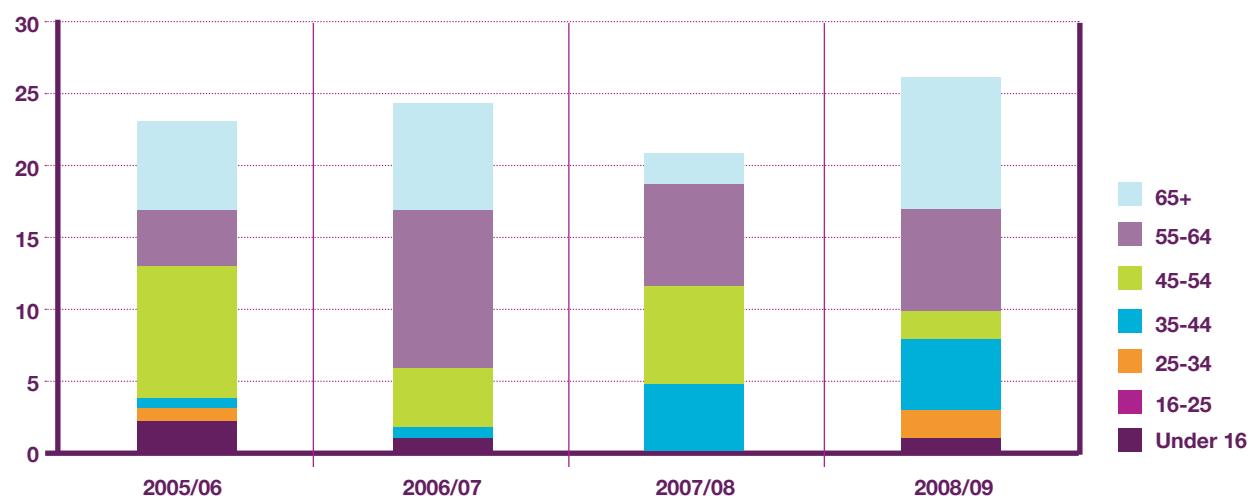
Source: WHSCT

As for the HSE North West area, the majority of admissions to hospital with one of the conditions covered by ARBI were males aged over 55. It is interesting to note that the proportion of overall admissions within the age range 45-54 (23%) was higher than the HSE North West area (16%) over the period and the number of admissions in those aged over 65 has fallen from the peak in 2005/06.

Figure 11:

WHSCT – Male ARBI Admissions to Hospital by Age (2005/06 – 2008/09)

WHSCT - MALE ARBI Admissions by Age

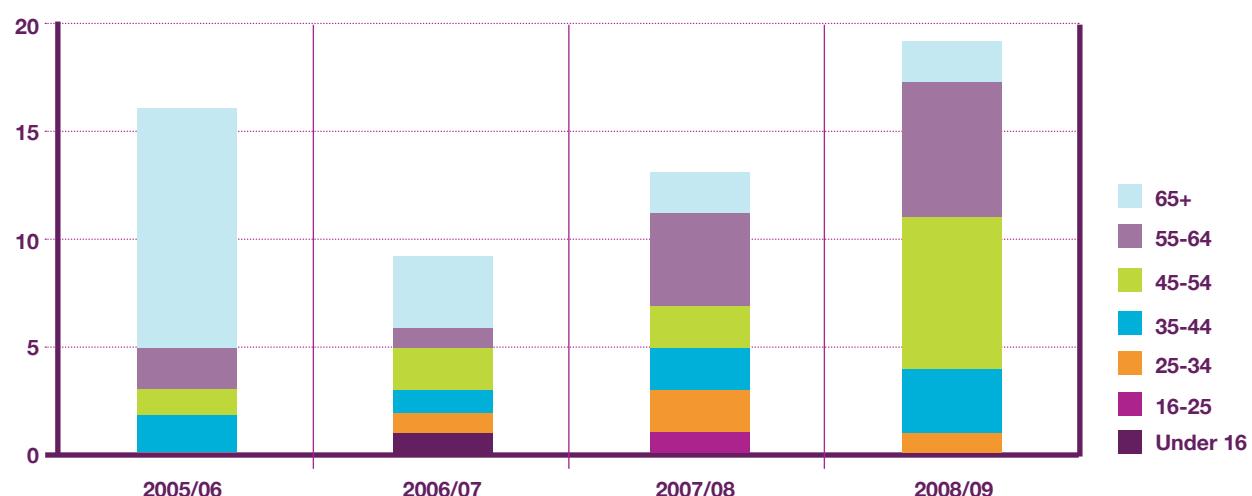


Source: WHSCT

Figure 12:

WHSCT – Female ARBI Admissions to Hospital by Age (2005/06 – 2008/09)

WHSCT - Female ARBI Admissions by Age



Source: WHSCT

In line with the profile outlined in the literature review, 56.4% of male admissions to hospitals in the WHSCT over the period were aged over 55 and 54.4% of female admissions to hospitals in the WHSCT over the period were aged over 55.

Table 12:

WHSCT – ARBI Admissions to Acute Hospital by Council Area of Residence (2005/06 – 2009/10)

Year	Hospital	Council Area of Residence					
		Derry City Council	Fermanagh District Council	Limavady Borough Council	Omagh District Council	Strabane District Council	Other
2005/06	Tyrone County	-	-	-	2	-	-
	Erne	-	5	-	-	-	-
	Altnagelvin	20	-	2	-	6	Coleraine Borough Council - 1
2006/07	Tyrone County	-	1	-	10	1	-
	Erne	-	4	-	-	-	-
	Altnagelvin	11	-	2	1	1	Ballymoney Borough Council - 1 Unknown - 1
2007/08	Tyrone County	-	-	-	5	1	-
	Erne	-	5	-	1	-	-
	Altnagelvin	14	-	3	-	4	Dungannon & South Tyrone Borough Council - 1
2008/09	Tyrone County	-	-	-	5	1	-
	Erne	1	9	-	2	-	Dungannon & South Tyrone Borough Council - 1
	Altnagelvin	16	-	1	1	6	Non NI - 2
Total		62	24	8	27	20	7

Source: WHSCT

As would be expected, the majority of admissions to each hospital are from people living within the traditional catchment area for the hospital.

Table 13:

WHSCT – ARBI Admissions to Acute Hospital by Destination on Discharge (2005/06 – 2008/09)

Year	Hospital	Destination on Discharge									
		Home	Usual residence	NHS General Hospital in NI	Other Hospital (Gen/A&E)	Private Residential Accommodation	NHS Residential Accommodation	Residential Accommodation (Non NHS)	NHS Mental Hospital in NI	Other Hospital (MH/MI)	Unknown
2005 /06	Tyrone County	1	-	-	1	-	-	-	-	-	-
	Erne	6	-	-	1	-	-	-	-	-	1
	Altnagelvin	-	13	2	-	-	1	-	2	-	11
2006 /07	Tyrone County	7	-	-	3	-	-	1	-	1	-
	Erne	1	-	-	1	-	-	-	-	1	1
	Altnagelvin	-	14	-	-	1	-	-	-	-	2
2007 /08	Tyrone County	3	-	-	2	-	-	-	-	-	1
	Erne	2	-	-	1	-	-	2	-	-	1
	Altnagelvin	-	15	1	-	-	-	-	-	-	6
2008 /09	Tyrone County	4	-	-	-	-	-	-	1	-	1
	Erne	9	-	-	1	-	-	1	-	-	2
	Altnagelvin	-	21	1	-	1	-	-	-	-	3
Total		33	63	4	10	2	1	4	3	2	29

Source: WHSCT

The majority of people admitted with an ARBI coding returned to their usual residence on discharge from hospital (41%), followed by a return to their home (22%). Of those being discharged, the destination was not known for 19% of people.

Table 14:

WHSCT – Number of ARBI Admissions to Hospital by Condition and Diagnosis (2005/06)

2005/06						
Condition	Tyrone County		Erne		Altnagelvin	
	Primary Diagnosis	Secondary diagnosis	Primary Diagnosis	Secondary diagnosis	Primary Diagnosis	Secondary diagnosis
Cerebellar Atrophy	-	-	-	-	2	2
Peripheral Neuropathy	-	-	-	-	-	3
Hepatic Encephalopathy	-	2	-	7	7	11
Frontal Lobe Dysfunction	-	-	-	1	2	1
Wernicke's Encephalopathy	-	-	-	-	-	-
Korsakoff's Amnesic Syndrome	-	-	-	-	1	1

Source: WHSCT

Table 15:

WHSCT – Number of ARBI Admissions to Hospital by Condition and Diagnosis (2006/07)

2006/07						
Condition	Tyrone County		Erne		Altnagelvin	
	Primary Diagnosis	Secondary diagnosis	Primary Diagnosis	Secondary diagnosis	Primary Diagnosis	Secondary diagnosis
Cerebellar Atrophy	-	6	-	-	3	1
Peripheral Neuropathy	-	-	1	-	3	3
Hepatic Encephalopathy	3	1	2	1	1	3
Frontal Lobe Dysfunction	-	-	-	-	1	1
Wernicke's Encephalopathy	-	-	-	-	-	-
Korsakoff's Amnesic Syndrome	-	2	-	-	1	-

Source: WHSCT

Table 16:

WHSCT – Number of ARBI Admissions to Hospital by Condition and Diagnosis (2007/08)

2007/08						
Condition	Tyrone County		Erne		Altnagelvin	
	Primary Diagnosis	Secondary diagnosis	Primary Diagnosis	Secondary diagnosis	Primary Diagnosis	Secondary diagnosis
Cerebellar Atrophy	-	-	-	-	-	3
Peripheral Neuropathy	-	1	-	-	1	3
Hepatic Encephalopathy	2	2	5	-	8	6
Frontal Lobe Dysfunction	-	-	-	-	-	2
Wernicke's Encephalopathy	-	-	-	-	-	-
Korsakoff's Amnesic Syndrome	-	1	1	-	-	-

Source: WHSCT

Table 17:

WHSCT – Number of ARBI Admissions to Hospital by Condition and Diagnosis (2008/09)

2008/09						
Condition	Tyrone County		Erne		Altnagelvin	
	Primary Diagnosis	Secondary diagnosis	Primary Diagnosis	Secondary diagnosis	Primary Diagnosis	Secondary diagnosis
Cerebellar Atrophy	-	1	-	2	1	7
Peripheral Neuropathy	-	-	-	-	1	3
Hepatic Encephalopathy	1	2	3	3	3	4
Frontal Lobe Dysfunction	1	1	-	2	1	3
Wernicke's Encephalopathy	-	-	-	-	-	-
Korsakoff's Amnesic Syndrome	-	-	-	3	-	3

Source: WHSCT

As stated previously, there were no admissions with a coding of Wernicke's Encephalopathy over the period. Only one admission to an acute hospital in the WHSCT over the period was given a primary diagnosis of Korsakoff's Amnesic Syndrome, with the remaining admissions noting a secondary diagnosis of Korsakoff's. The number of admissions with a coding of Korsakoff's increased by 200% from two in 2005/06 to six in 2008/09.

Key Points

- There has been a recognition by health professionals that a high degree of under-reporting in the data collected is likely, due to difficulties in bringing people to a position where a diagnosis can be made, the complexities involved in making a diagnosis, the resources involved and data protocols only recording the primary and maybe one or two secondary diagnoses.
- The data collected only relates to acute hospitals. There may be individuals in nursing homes or mental health facilities who have ARBI and these are not captured here.
- These figures represent admissions for the eight conditions specified for ARBI for the purposes of this report. As highlighted by some health professionals we interviewed there are potentially other conditions such as alcohol-related dementia that are not included within this data collection.
- The reported admissions rate with an ARBI coding in both the Republic of Ireland and Northern Ireland between the years of 2005 to 2009 was low and relatively stable with an average of 32.6 admissions per year in the HSE North West area and 37.7 admissions per year in the WHSCT. It is not possible to tell at this stage exactly how many of these may be an individual being admitted more than once.
- In both areas, the majority of admissions were from male patients (68% in the HSE North West and 62% in the WHSCT).
- The majority of people admitted to hospitals in both jurisdictions were aged over 55. The majority of males admitted to hospitals with an ARBI coding in both jurisdictions are aged over 55 (61.7% of male admissions in the HSE North West area and 56.4% of male admissions to hospitals in the WHSCT over the period were aged over 55). Most females admitted to hospitals in both jurisdictions were also aged over 55 (62.5% of female admissions in the HSE North West area and 54.4% of female admissions to hospitals in the WHSCT over the period were aged over 55).
- There were a number of admissions from people aged under 24 during the period (seven in the HSE North West and six in the WHSCT). We note however that it is unlikely that these are due to an alcohol-related condition and recommend that further research is conducted to determine whether, for example, hepatic encephalopathy can be diagnosed without alcohol being a factor.
- 51% of the total admissions in the WHSCT over the period were for Hepatic Encephalopathy, followed by Cerebellar Atrophy (18.5%), Peripheral Neuropathy and Frontal Lobe Dysfunction (10.6% each) and Korsakoff's Amnesic Syndrome (8.6% each).
- No admissions for Wernicke's Encephalopathy were recorded in the WHSCT during the period.

5.2.3 Anecdotal Evidence

The difficulties in obtaining accurate data on the incidences of ARBI and the potential for under-reporting have been noted, particularly with regard to:

- Services not always capturing data past one or two secondary diagnoses
- Formats and protocols for data collection may vary between services and jurisdictions
- Difficulties in being able to make a complete assessment and diagnosis of an individual with suspected ARBI
- Which service(s) has lead responsibility for this condition.
- We therefore also asked some of those interviewed for an indication of the prevalence based on their experience. Those who responded stated that they would come across two to four people with ARBI each year and could maybe say that ten or so more people may have ARBI but all acknowledged that this represented a significant level of under-reporting. Data also noted that there were 5 people with ARBI across the 11 community hospital sites in the HSE (Donegal) area. Within the community hospitals Difficulties in identifying people with ARBI were highlighted as follows:
- Only Consultants can make a diagnosis – often someone such as a member of an addiction team, nursing staff or a supported accommodation manager would suspect that a person has ARBI,

but they are unable to have this confirmed with a clinical diagnosis (sometimes due to a shortage of Consultants or Consultant time or due to the difficulties involved in making an individual ready and keeping them engaged for assessment – see next point)

- Making a clinical diagnosis is very complex and involves a number of specialists from psychiatry, neuropsychology, occupational therapy and addiction. A complete diagnosis can only be made once a person has been abstinent from alcohol for at least three-six months, which can be difficult for someone with ARBI to maintain if they are not in supported accommodation that restricts the use of alcohol as a person with ARBI will not necessarily have the cognitive capacity to remember that they must not be drinking
- People with ARBI (and those with an alcohol addiction) often disengage from health services before they can be fully assessed
- A diagnosis of Korsakoff's for example may be secondary to another condition. If the diagnosis of Korsakoff's falls as the fifth secondary diagnosis say, it may not be captured if services are only recording the primary (or presenting) and maybe one or two secondary diagnoses. Within the acute sector this may also impact if, due to the limited number of secondary diagnoses that can be recorded, the focus is on presenting the physical conditions rather than, for example, a mental health diagnosis.

5.3 Current Care Pathway

Health professionals from both jurisdictions stated during interview that there are currently no defined care pathways within the HSE North West or WHSCT areas for people with ARBI (including those who would fall within a broader definition of brain damage as a result of alcohol).

Whilst it may be the case that professionals are notified of suspected cases of, for example, Korsakoff's there are no ready screening or assessment tools within either health jurisdiction to confirm this. In order to make a complete assessment of Korsakoff's a range of general intellectual functioning tests are completed together with a cognitive profile. The assessment may take a number of sessions and liaison with family members and carers to build a picture of the individual and establish issues such as confabulation. The individual will also be assessed by psychiatry, neuropsychology and the addiction team before a full diagnosis can be made. A complicating factor in making this complex assessment is that the individual must have been abstinent from alcohol for at least three months (although a Consultant Psychologist interviewed indicated that abstinence from alcohol for six months would be more appropriate). It was noted therefore that whilst there may be general suspicions of Korsakoff's, an individual may self-discharge from hospital and resume drinking alcohol if in an unsupported environment, meaning that a formal diagnosis of Korsakoff's cannot be made.

A number of people from both health jurisdictions interviewed noted that up until five or six years ago people with ARBI would have been cared for within long-stay psychiatric facilities under the remit of mental health services. Whilst this did not necessarily provide the person with ARBI with appropriate treatment and/or rehabilitation, it was noted that it did offer a place of safety for the individuals concerned and ensured that their basic needs, such as good nutrition and a secure environment, were met. With the move at national policy level in both jurisdictions away from long-term in-patient care within traditional psychiatric institutions to a policy of continuing care in the community, those interviewed highlighted that people with ARBI do not fit the profile for

in-patient psychiatric care and/or there are no longer the resources or residential facilities for looking after people ARBI.

The current service model of both the HSE North West and WHSCT does not easily facilitate a person with ARBI – whilst they may require elements of a number of different services (such as psychiatry, psychology and addictions treatment), they do not fit neatly into any of these services (some uncertainty was expressed during interview as to whether people with ARBI should fall under the remit of mental health services or brain injury services). Additionally given current service pressures and service model, services are not equipped or may not have the capacity and especially resourcing to treat ARBI. This can lead to an individual being 'bounced' from service to service.

A number of health professionals also stated that, as there is no formal care pathway for people with ARBI, people with a high level of care needs may be placed in inappropriate care settings such as older people's homes or dementia care settings, particularly if they are under 65 years old. Some stated however that, whilst imperfect, these settings do at least ensure that the individual is placed in a secure environment, is fed well and their access to alcohol will be restricted. It should be noted however that placing an individual in, for example, a community hospital would not necessarily be more cost effective: a bed in a community hospital in Donegal currently costs €1,365 per week and between €700 and €750 in a private nursing home and if individuals can be stabilised, it may be that the level of nursing care provided in a community hospital is higher than required.

The issue of a care setting or accommodation is further compounded if an individual is still drinking as many settings and accommodation providers will not take people who drink heavily or misuse alcohol. This can result in people with ARBI living, for example, in short-term hostel accommodation but without any formal diagnosis of ARBI or programme of care. This was evidenced in discussions with two short-term accommodation providers for men (House in the Wells)

and women (Foyle Valley House) in Derry who noted that they may have one or two individuals who they would consider might meet the criteria for Korsakoff's but who are not receiving treatment. They noted that the short-term accommodation is not the ideal setting for these individuals as the accommodation providers do not have any specialist knowledge, skills or services in order to deal with ARBI.

An additional issue within the HSE in Donegal was highlighted as the absence of routine detoxification services – it was noted that all detoxifications were carried out as emergencies through the HSE and that these were often only short detoxes due to the volume rather than the longer period of a few weeks that might be required for someone with ARBI⁴⁴. As noted earlier, the Report of the HSE Working Group on Residential Treatment & Rehabilitation (Substance Abuse) (2007) found that in the border corridor (counties Donegal, Leitrim, Sligo, Cavan, Monaghan and Louth) there are:

- No stabilisation services
- No community-based residential detox units
- No medical detoxification units.

The report concludes that there are inadequate levels of residential services in the Republic of Ireland and in particular detoxification services and recommends that there should be 15 alcohol detoxification beds for each of the four HSE administrative regions.

A report in 2008 into the impact of alcohol on health services in Letterkenny General and Altnagelvin Hospitals found that the economic burden of alcohol on both hospitals was a conservative £8.1 million/€9.3 million but could more realistically be as much as £32 Million/ €37 million. The report noted that for general facilities for those misusing alcohol, whilst “the two hospitals provide immediate access to detox facilities for dependent drinkers, other alcohol treatment services are sometimes less accessible than they should be.”⁴⁵ The report identified an economic burden due to alcohol. With regard to detox, the report notes that the number of admissions to Letterkenny General Hospital for alcohol detoxification more than trebled over the period 2005-2007. The average number of bed days per detox admission was noted as 3-3.4, although it was considered

that 5-8 days detox would be preferable to avoid further readmissions.

Within the WHSCT an Alcohol Liaison Nurse is based at each of the Erne and Altnagelvin Hospitals. The Alcohol Liaison Nurses are based within the A&E Departments of each hospital and provide a support to the identification and referral of patients who are identified as heavy alcohol users. The Alcohol Liaison Nurses use the Paddington Alcohol Test (PAT) to screen assist patients to identify their level of alcohol use and offer brief counselling and interventions for people that are PAT positive or who are being detoxed. The Nurses also provide support and training to staff in relation to alcohol issues. It is not clear however that their work specifically focuses on those with ARBI or potentially with ARBI as a separate care group.

The WHSCT has recently commenced a home alcohol detox service and is working on early discharge for hospital detoxes with individuals being followed up in the community as a tail end detox. Thiamine is prescribed in tablet form for community detoxes whilst tail end detoxes (those who start at the hospital and are discharged early to the Community Addiction Teams to continue detox) have Pabrinex whilst in hospital. The WHSCT aims in the future to develop a protocol that would allow IM Pabrinex to be given as part of a home detox as well as in a hospital setting.

Despite the lack of a formal care pathway and difficulties in making a diagnosis, a case management model is being developed in the HSE West (Donegal). This is the first time that such a model has been implemented, primarily due to the difficulties in making complete assessments and in providing suitable ongoing accommodation. In developing this model, much work was required by psychiatry, addiction, Nursing services Community Hospitals and neuropsychology services together to complete the formal assessment. Following this, the multi-disciplinary team was broadened to develop the specific care and treatment package, including day activity programmes, occupational therapy, community mental health nursing, social work services and primary care. It was noted that this is very much a new approach and something that is still being developed. Although there were challenges in coordinating the elements of service required and the associated budgetary considerations,

45. The Economic Burden of Alcohol on Letterkenny General Hospital and Altnagelvin Hospital, Williamson Consulting, 2008

the willingness and flexibility of staff to meet the needs of the individual was cited as a key success in developing the model. The support of senior management was also noted as a key support in driving the model forwards.

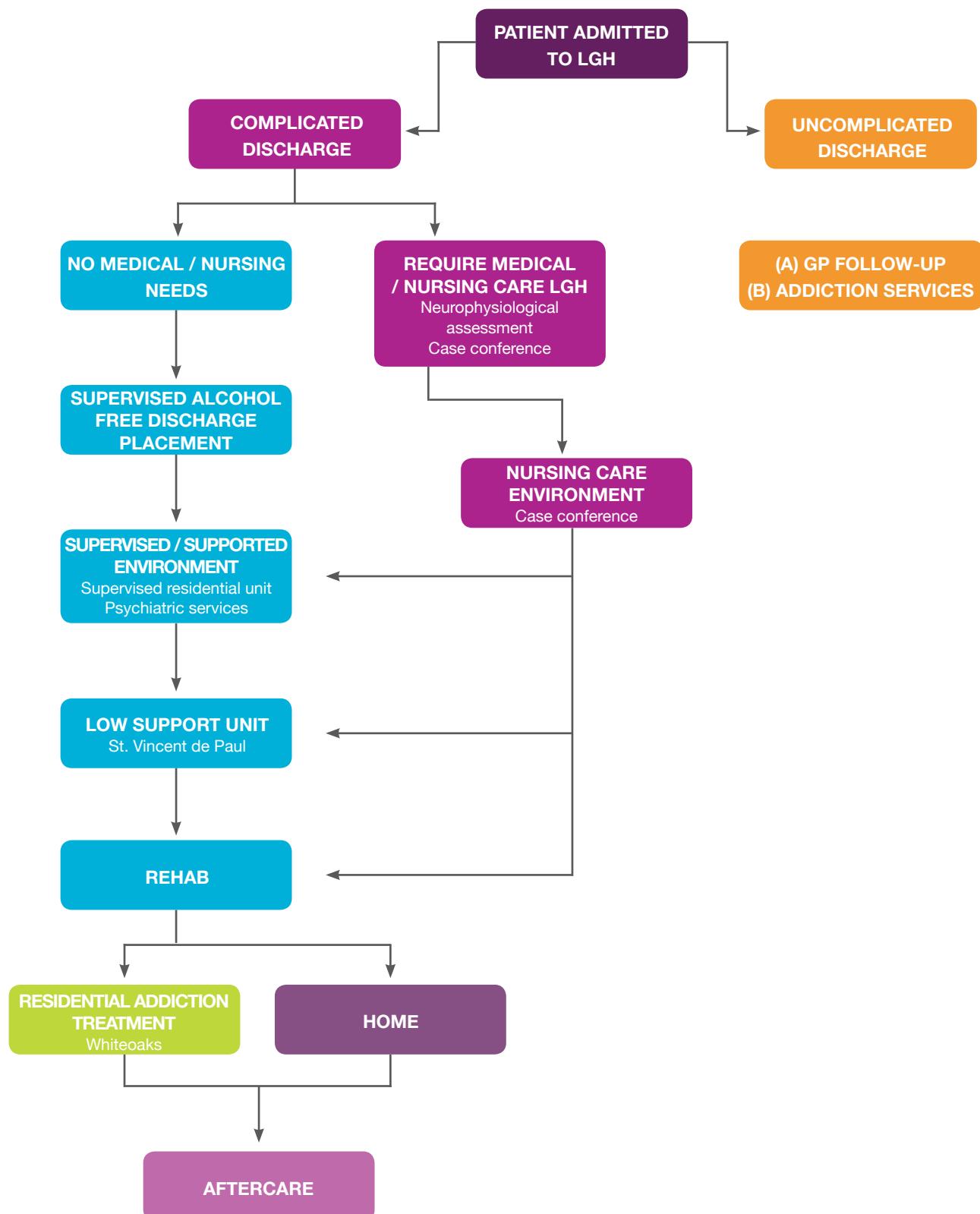
This case management model is very much in its infancy and there are still important questions to work through, for example which service will have responsibility for the individual in the longer term and, if this is to be repeated, who will take responsibility for the coordination between services if case managers are not to be appointed. Additional challenges were noted in that, if case managers are appointed, will they be drawn from existing staff (in which case what happens to their existing case loads) or will they be new appointments (in which case how are they funded and under which service would they be housed)?

In terms of care pathways within the rest of Ireland, a Needs Assessment Survey of People with Acquired Brain Injury in the Mid-West Region featured in the National Institute of Health Sciences Research Bulletin (Vol. 3, Issue 4, 2006) included people with ARBI as a sub-group of people with an ABI. This needs assessment highlighted that "...an appreciable improvement in the availability and frequency of service provision for medical/paramedical and community (non-medical) services is required" and concluded that the survey had "indicated the need for the Disability Services Directorate to develop a more comprehensive and broad-based range of services for people with an acquired brain injury."

Despite the lack of a formal care pathway for people with ARBI, work has been undertaken in the HSE (Donegal) to develop a discharge pathway for patients with ARBI. The discharge pathway is illustrated in Figure 13.

Table 13:

Discharge Pathway for Patients with ARBI (HSE Donegal, 2009)



The key messages which emerged from the literature review and a review of the policy and strategy documents in the Republic of Ireland and Northern Ireland were echoed in the various meetings and discussions held with key staff locally. In summary, the key issues highlighted in the local discussions were:

Challenges in Making ARBI Assessments

- A lack of clarity in terms of the underlying way of dealing with people with ARBI and in which service they should be placed. One person put this very succinctly by posing the question “Whose problem is it?”
- Some of those interviewed said that, whilst there was no single data source to quantify precisely the incidence and prevalence of ARBI, anecdotally the picture emerging was that it is a growing problem
- People with ARBI, especially those who present a more established condition, can be placed in inappropriate care settings. A significant point made during interviews was that “If there was a clear diagnosis that ARBI was a brain injury (whether as a result of alcohol or a car accident) people would be placed in appropriate programmes of care and settings”
- One of the main themes which ran through the views expressed locally was that people who had severe problems as a result of ARBI did not have the cognitive capacity to complete programmes of treatment (such as addiction programmes), especially those which require abstinence from alcohol. This problem was described starkly by one person who said that, “The difficulty is, if the person has ARBI or cognitive difficulties, then they will find it extremely difficult to abstain from alcohol by themselves because they simply will not remember that they should not be drinking”
- An undercurrent running through some of the discussions locally was that the disruptive nature of people with chronic problems as a result of ARBI can cause challenges in placing them within established programmes of care or accommodation which are not specifically tailored for ARBI. One person expressed the practical realities in saying that, “Even if people could get a diagnosis, there is nowhere to put them”
- Given the disruptive nature of some people with severe problems caused by ARBI, there are social barriers to overcome, including securing accommodation from landlords. These challenges faced by people with ARBI were well expressed by one person interviewed who said, “There is a moral judgement made about people with ARBI that they brought it on themselves”
- Arguably, a key issue to be addressed is that there does not appear to be a dedicated ARBI policy supported by funding. This was illustrated by one person interviewed who said, “Policy drivers are not there so there is no push for ARBI services.” As a result, the view expressed was that, understandably therefore, ARBI was not given priority status in comparison with other service pressures.
- The Burden of Cost of alcohol in Letterkenny and Altnagelvin Hospitals in 2008 found that the economic burden of alcohol on both hospitals was a conservative £8.1 million/€9.3 million but could more realistically be as much as £32 Million/ €37 million

6. Conclusions and Recommendations

6.1 Conclusions

ARBI covers a number of conditions, although the most directly-related to chronic alcohol misuse are Korsakoff's Amnesic Syndrome and Wernicke's Encephalopathy, and presents a number of challenges in terms of policy and service delivery. A key practical problem appears to be that people with ARBI do not fit neatly within any of the existing health services and may therefore pass from service to service or fall through the net. The lack of a policy driver for ARBI at a more strategic level in both the Republic of Ireland and Northern Ireland can also lead to individuals being placed in inappropriate care settings or not receiving the full support required.

Analysis of the data collected as part of the research for this report notes that reported admissions rates with an ARBI coding in both the Republic of Ireland and Northern Ireland between the years of 2005 to 2009 were an average of 32.6 admissions per year in the HSE North West area and 37.7 admissions per year in the WHSCT. In both areas, the majority of admissions were from male patients (68% in the HSE North West and 62% in the WHSCT).

Based on our research we note that the key challenges facing the health and social care system are:

- No clear system for capturing data on the prevalence of the condition
- No protocol on coding for this condition
- No clear pathway of care for ARBI
- No clearly identified lead care group for ARBI
- No quick or easy means of assessing and diagnosing someone with ARBI, particularly if an individual is required to abstain from alcohol for six months in order to complete a full assessment
- Often the individual presenting has an established condition and does not have the cognitive capacity to successfully undergo treatment programmes, especially those which require abstinence from alcohol.
- Significant burden of cost due to alcohol related conditions

- Need for a public health campaign to raise public awareness on ARBI

The above challenges result in a number of key dilemmas, principally:

- Anecdotally health and care staff state that the prevalence of ARBI is growing, but there is no systematic way of capturing data conclusively. This, understandably, results in difficulties in developing service solutions to what is essentially an unquantified problem
- The absence of a clear pathway of care centred on a systematic assessment and diagnosis means that there can be no coordinated approach to providing the many elements of care and treatment for an individual with ARBI
- Within the current service model, the lack of agreement as to whether ARBI is principally seen as a mental health condition or a brain injury results in a dilemma as to which pathway of care the patient should follow.

6.2 Recommendations

In response to the issues identified, in terms of general strategy, through the literature review and local context and taking into account the current financial climate, we would make the following recommendations:

In the short-term:

- The current lack of ready information makes it difficult to accurately assess the extent of the issue. Consideration should be given to ensuring that coding and data on the spectrum of ARBI is accurately and comprehensively captured across both all areas of the health service, from acute and psychiatric facilities to community services such as addiction and community hospitals, to allow effective decision-making in service planning. A protocol on coding for this condition should be agreed
- Work should be undertaken to consider how best to support full diagnosis of ARBI given that people may be entering health system via a number of different points and services. In particular the issue of how best to assist individuals to abstain from alcohol for long enough to allow the assessment to be completed, such as the use of sheltered accommodation during the assessment period, should be considered
- Consideration should be given to developing key messages to raise awareness among health and care staff, the general public and patients and carers in relation to ARBI. Information and awareness-raising in conjunction with the development of a formal care pathway for ARBI would help to raise awareness of ARBI at an earlier stage of the condition when there is the greatest potential for providing rehabilitation to independent living and provide access to services more quickly. This includes enabling primary care staff, such as GPs, and other front-line health professionals, who are likely to come into contact with individuals at a much earlier stage of the condition, to identify ARBI and put in place effective treatments, such as detoxification, as preventative measures or to aid effective diagnosis.
- Awareness-raising amongst the public, in conjunction with other initiatives to raise awareness of the dangers of the misuse of alcohol, may also help to

prevent hazardous and addictive drinking that may lead to ARBI

- Ensure that detoxification services provided within each health jurisdiction meet the needs of people with ARBI or to prevent conditions such as Korsakoff's or Wernicke's Encephalopathy occurring. In particular, ensure that the recommended number of alcohol detoxification beds (15) determined by the Report of the HSE Working Group on Residential Treatment & Rehabilitation (Substance Abuse) (2007) as required in the HSE West are in place. There is also need to ensure GP and/or community detoxification to meet the needs of individuals and seek to prevent ARBI developing or halt initial progress
- All alcohol detoxification sites whether in acute or community settings should have a protocol on the appropriate prescribing of Thiamine
- The current service model of both health jurisdictions does not easily facilitate a person with ARBI who may require elements of a number of different services (such as psychology, occupational therapy, primary care, physical and sensory disability, psychiatry and addictions treatment). The case management model currently being implemented in the HSE West (Donegal), bringing together a multi-disciplinary team, should continue to be developed therefore and shaped in order to support more people with a diagnosis of ARBI. The potential for expanding the case management approach, based on a person-centred pathway of care and supported by a multi-disciplinary team and dedicated case workers, should be explored
- Recognising that the development of the case management model will not be a 'quick fix' consideration should be given to practical steps that could be taken in the meantime to ease the burden for families and carers by providing respite care and support workers
- Consideration should be given on how best to plan for the long-term residential care of ARBI patients as a priority. All future planning should be underpinned by a recovery-focused model and guided in the

HSE West by the National Drug Treatment and Rehabilitation Framework 2009

- Ensure that all people with ARBI being discharged from inpatient acute hospital settings have an integrated discharge plan in conjunction with family members (if available)
- Maintain attention on the outcome of the UK pilot as a driver to inform future coding practice in Ireland's acute hospitals.
- Training in ARBI identification needs to be prioritised within the National Addiction training programmes.
- Dedicated psychiatric beds for rehabilitation and continuing care are needed for the sub-group of people with ARBI who have major behavioural or psychiatric difficulties.
- Examine the role of Drug Task Forces or Co-ordination Teams in creation of a multi-disciplinary and inter-agency approach to assessment

Cross-border work and taking a longer-term approach:

- A cross-border approach should be taken to the issue of ARBI, given the need for a critical mass of population to sustain a service and to deal with the shared risk of developing services within the current difficult economic climate. The possibility of using the CAWT structures to facilitate this cross-border approach could be explored
- Consideration should be given to broadening the discussions to include those people with brain damage caused by alcohol (such as alcohol-related dementia or traumatic brain injury associated with alcohol) to ensure that an integrated approach to care and treatment is developed
- This work initiated by the NWAF with the HSE in Donegal to look at pathways of care should be supported on a cross-border basis. All those interviewed indicated that a multi-disciplinary case management approach was required for ARBI services. The potential to establish an ARBI service/multi-disciplinary team on a cross-border basis, with access to an ARBI funding pool to pay

for the various service elements required and a case worker to coordinate communication between the various service elements, would allow the creation of a specialist team that could streamline services provided to people with ARBI and improve care pathways. Whilst ARBI differs from an ABI in its nature and treatment, the care pathway for people with ABI in the HSE North West area could be adapted appropriately for those with ARBI, particularly if a Case Coordinator is put in place to coordinate the multi-disciplinary care and treatment package required for an individual with ARBI:

Table 14:

Care Pathway for Community Acquired Brain Injury Service (Community ABI Service, Sligo & Leitrim)



- Develop an inter-agency cross-border approach to addressing the varying accommodation requirements of people with ARBI, from supported accommodation to stabilise an individual and assist them to abstain from alcohol prior to assessment, to more long-term accommodation once a person is receiving care and treatment – for some at the more severe end of the condition, this may be 24-hour care, whilst for others it may be independent living. Within this context, thought should be given to engaging with the not-for-profit and private sectors to provide places within specialist nursing or care homes or developing dedicated rehabilitation or accommodation units – it may be the case that this is developed on a national basis, rather than a regional basis, to provide the mass of population required to sustain such a service
- Consideration should be given to the best means of providing support and maintaining abstinence from alcohol for people with ARBI
- The NWAF should review opportunities to highlight the issue of ARBI at a national level with a view to influencing policy development on ARBI.

Appendix A

Integrated Care Pathways for Mild and Moderate to Severe Acquired Brain Injury (DHSSPS, NI)

Table 15:
Integrated Care Pathway for Mild Acquired Brain Injury (DHSSPS, NI)

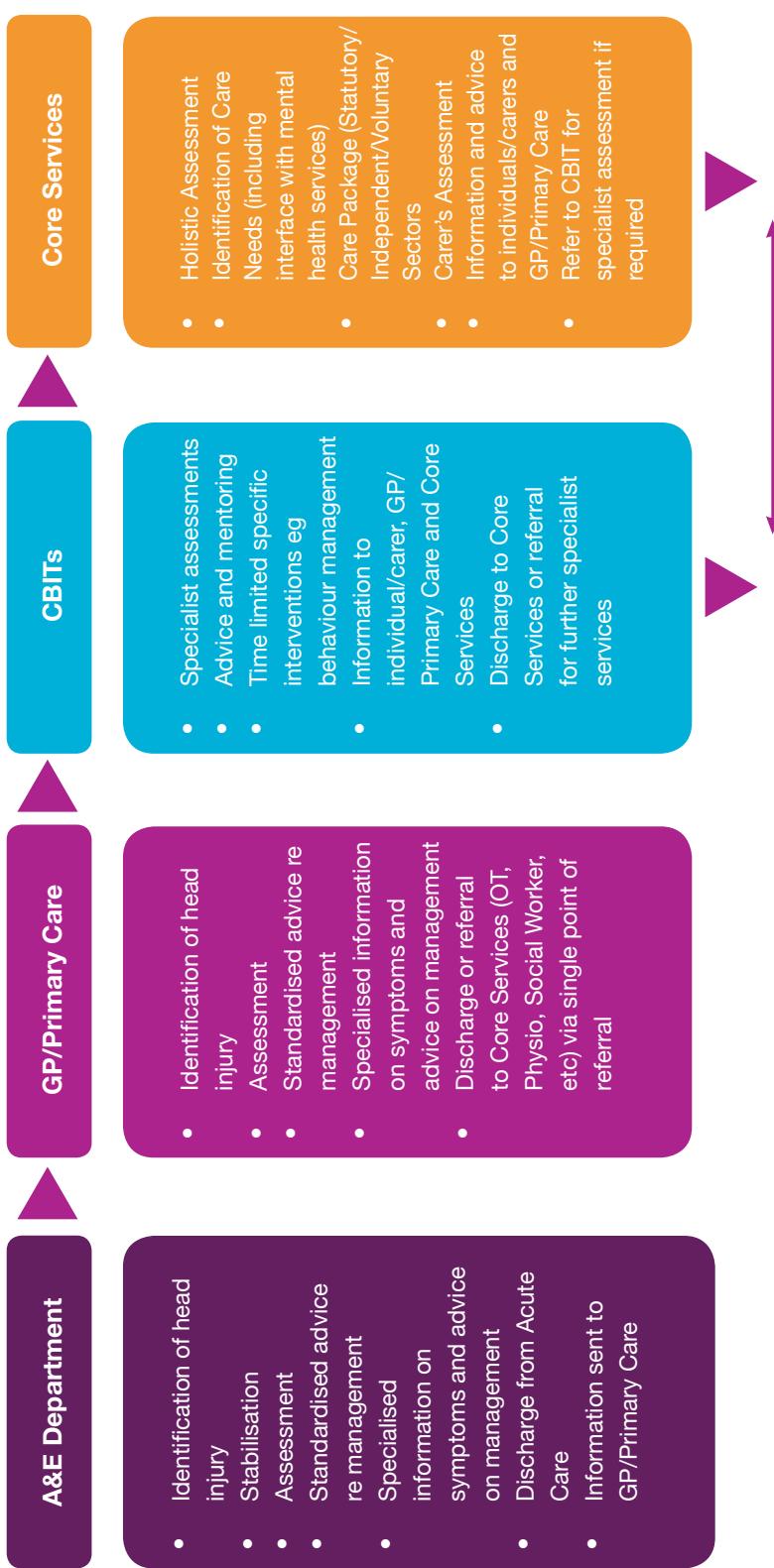
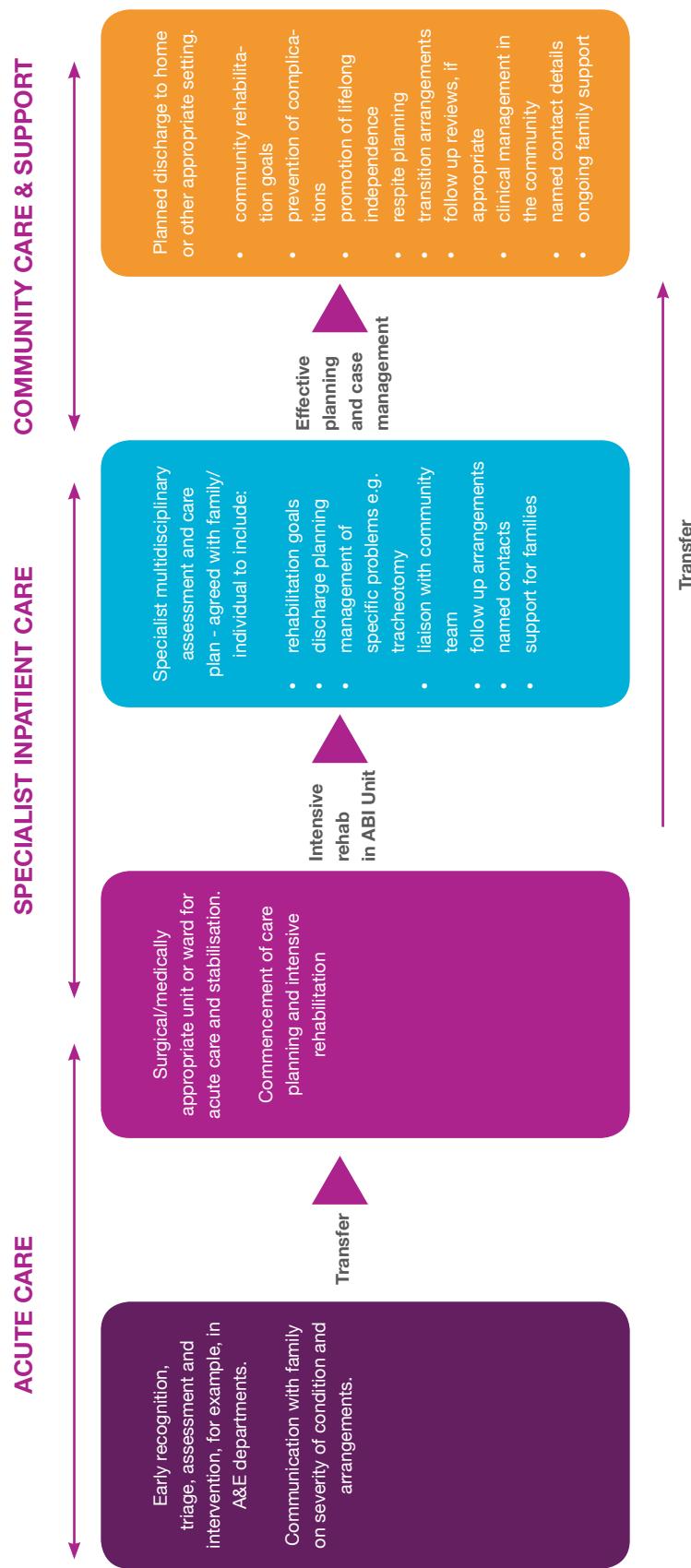


Table 16:
Integrated Care Pathway for Moderate to Severe Acquired Brain Injury (DHSSPS, NI)



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**North West Alcohol Forum Ltd**

Unit B9, Enterprise Fund Business Park,
Ballyraine, Letterkenny,
Co Donegal.

Tel: 074 9125596
info@nwaf.ie
www.nwaf.ie

