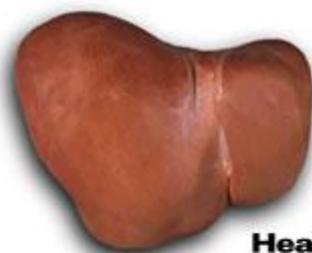


The economic cost and health burden of liver diseases in Australia

The Gastroenterological Society of Australia/Australian Liver Association

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Healthy



Cirrhosis

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Glossary of acronyms

ABS	Australian Bureau of Statistics
AHA	Australasian Hepatology Association
ALA	Australian Liver Association
ALT	alanine aminotransferase
AIHW	Australian Institute of Health and Welfare
ALD	alcoholic liver disease
ALT	alanine aminotransferase
ANAO	Australian National Audit Office
AWE	average weekly earnings
CA	Carer Allowance
CP	Carer Payment
CPI	consumer price index
DALY	disability adjusted life year
DHS	Department of Human Services
DW	disability weight
DWL	deadweight loss
GESA	Gastroenterological Society of Australia
GP	general practitioner
ICD	International Classification of Diseases
NAFLD	non-alcoholic fatty liver disease
NHMD	National Hospital Morbidity Database
NHMRC	National Health and Medical Research Council
NPDI	National Perinatal Depression Initiative
NPV	net present value
NRCP	national respite for carers program
PBC	primary biliary cirrhosis
PSC	primary sclerosing cholangitis
SDAC	Survey of Disability, Ageing and Carers
SCRGSP	Steering Committee for the Review of Government Service Provision
US	United States
VSL	value of a statistical life
VSLY	value of a statistical life year
WTP	willingness to pay
YLD	years of healthy life lost due to disability
YLL	years of life lost due to premature death

Executive summary

The Gastroenterological Society of Australia (GESA) and Australian Liver Association (ALA) commissioned Deloitte Access Economics to calculate the prevalence, mortality and economic cost of liver diseases in Australia in 2012. The diseases considered were¹:

- hepatitis A, B and C;
- non-alcoholic fatty liver disease (NAFLD);
- liver cancer;
- alcoholic liver disease;
- cholestatic autoimmune liver disease, comprising primary biliary cirrhosis (PBC) and primary sclerosing cholangitis (PSC);
- haemochromatosis; and
- paediatric liver disease.

Prevalence

There is a paucity of contemporary Australian prevalence and mortality data available related to liver disease, in particular, data by age and gender. Several data sources were considered for this report including published and grey literature (such as government reports) and government websites (Department of Health and Ageing, Australian Institute of Health and Welfare (AIHW), NSW Health and Victorian Department of Health). International sources were also included. Members of the GESA expert reference group were contacted for assistance in retrieving data.

The most prevalent liver disease was found to be NAFLD which affects an estimated 5.5 million Australians, including 40% of all adults aged 50 years and above (Table i). PBC was the least common, only affecting around 400 Australians aged 35 years and above. Prevalence rates were also applied to the 2030 population projected by the Australian Bureau of Statistics (ABS, 2008) to estimate the number of Australians with liver disease in the future.

Table i: Prevalence of liver disease in Australia by age and gender, 2012 and 2030

Disease	2012			2030		
	Males	Females	Persons	Males	Females	Persons
Hepatitis A	148	135	284	180	164	344
Hepatitis B	105,555	105,535	211,089	131,782	131,061	262,842
Hepatitis C	185,468	121,572	307,040	251,391	162,887	414,278
NAFLD	2,713,372	2,825,305	5,538,677	3,566,969	3,693,619	7,260,588
Primary liver cancer	1,064	387	1,451	1,652	601	2,253
Alcoholic liver disease	4,605	1,598	6,203	5,816	2,008	7,824
PBC	43	389	433	63	553	616
PSC	554	318	872	748	425	1,174
Haemochromatosis	56,343	56,894	113,237	70,999	71,421	142,421
Total	3,067,152	3,112,133	6,179,285	4,029,600	4,062,739	8,092,339

Note: Total may not equal sum of parts due to rounding. The estimates in Table i represent cases of liver disease – the number of people with liver disease is not the total as a person may have more than one liver condition.

¹ Note that auto immune hepatitis was not considered due to lack of data.

Mortality

Population mortality rates were likewise difficult to obtain for most of the liver disease subtypes and were retrieved from a variety of sources including published papers, grey literature and expert opinion. Hepatitis C was responsible for the highest number of deaths (2,550 estimated for 2012). The mortality of people with Hepatitis A, PBC and haemochromatosis were considered to be on par with that of the general Australian population, so no deaths were attributable to these conditions.

Table ii: Deaths by liver disease in Australia by age and gender, 2012

Disease	Males	Females	Persons
Hepatitis A	0	0	0
Hepatitis B	183	202	386
Hepatitis C	1,977	573	2,550
Non-alcoholic fatty liver disease	1,154	1,110	2,264
Primary liver cancer	824	445	1,270
Alcoholic liver disease	579	201	780
Primary biliary cirrhosis	0	0	0
Primary sclerosing cholangitis	12	4	16
Haemochromatosis	0	0	0
Total	4,729	2,537	7,266

Note: Total may not equal the sum of the parts due to rounding.

Cost impacts of liver diseases

The health costs of treating liver disease in 2012 were estimated as \$432 million. This includes costs estimated by the AIHW of \$386 million (hospital admitted patient services, out-of-hospital medical services and prescription pharmaceuticals), the national immunisation program (\$34 million) and funding for liver disease-related research (\$12 million). Two-thirds of the AIHW health spend is for males, in particular, males aged between 35 and 74 years.

The productivity impacts of liver diseases were estimated as \$4.2 billion in 2012. Of this cost, \$1.9 billion was due to lost lifetime earnings by individuals who died prematurely due to liver diseases and \$2.1 billion due to productivity losses associated with lower employment participation. Absenteeism caused an additional cost of \$207 million. Productivity costs were borne largely by individuals, but also by Federal Government (in the form of less taxation revenue) and by employers (in the form of sick leave).

Informal care for people with liver diseases is often undertaken by family members or friends and represents an economic opportunity cost of approximately \$259 million in 2012, based on data from the Survey of Disability and Carers (SDAC) conducted by the ABS.

In addition there were program payments received by people with primary liver cancer totalling \$2 million, the cost of bringing forward funerals (\$34 million) and deadweight efficiency losses associated with transfers (taxation forgone and welfare payments) totalling \$527 million.

Burden of disease quantifies the impact that liver disease has on wellbeing, where pain, suffering and premature death are measured in terms of disability adjusted life years (DALYs). The **burden of disease resulting from liver diseases was estimated as \$45.3 billion in 2012.**

The total financial cost of liver disease was estimated as \$5.4 billion in Australia in 2012 and the total cost including the burden of disease is estimated to be \$50.7 billion (Table iii).

Table iii: Total costs, by type and bearer, 2012 (\$ million)

	Federal government	States and territories	Individuals	Other parties	Total
<u>Burden of Disease</u>			45,256.0		45,256.0
<u>Health system costs</u>					
Health expenditure	164.9	102.0	70.7	48.7	386.2
National immunisation program	14.5	9.0	6.2	4.3	34.0
Research funding	5.0	3.1	2.1	1.5	11.7
<u>Productivity costs</u>					
Employment	680.3		1,386.9		2,067.2
Absenteeism	68.2			139.0	207.1
Premature death	630.1		1,284.5		1,914.6
<u>Carer costs</u>	85.1		173.5		258.7
<u>Program payments</u>					
National respite for carers	0.3				0.3
Palliative care	1.6				1.6
<u>Funeral costs</u>			33.9		33.9
<u>Welfare payments</u>	53.7			-53.7	-
<u>Transfer DWLs</u>				526.8	526.8
Total	1,703.7	114.1	48,213.8	666.6	50,698.1

Note: Total may not equal the sum of the parts due to rounding.

Source: Deloitte Access Economics calculations.

Individuals bore 54%, Federal government 31%, state and territory governments 2% and others in society bore 12% of financial costs. Including burden of disease, individuals bore 95%.

Comparison with other diseases

The total estimated economic cost of liver diseases was higher than that of Type 2 diabetes – indeed, liver disease is approximately 40% more costly than Type 2 diabetes and chronic kidney diseases² combined. Liver disease is about 39% of the cost of cardiovascular disease, which is one of the most costly conditions in Australia (as is cancer).

Table iv presents the economic costs of Type 2 diabetes, chronic kidney diseases and cardiovascular diseases (which comprise a range of conditions including heart attack and stroke).

² Note that the costs associated with chronic kidney diseases in this case only relate to individuals with Type 2 diabetes.

Table iv: Comparison with other diseases, 2012 (\$ million)^(a)

	Type 2 Diabetes	Chronic kidney diseases ^(b)	Cardiovascular diseases	Liver diseases
BoD	\$22,182.0	\$679.8	\$113,715.8	\$45,256.0
Health System	\$1,261.0	\$516.3	\$5,717.3	\$431.9
Productivity	\$4,920.0	\$72.6	\$5,143.8	\$4,188.9
Carers	\$5,328.0	\$42.9	\$3,342.4	\$258.7
DWL	\$838.0	\$108.9	\$1,703.3	\$526.8
Other financial	\$77.0	\$3.8	\$0.0	\$35.8
Total financial	\$12,424.0	\$744.5	\$15,906.7	\$5,442.1
Total incl. BoD	\$34,606.0	\$1,424.4	\$129,622.5	\$50,698.1

Note: (a) The costs for diabetes, chronic kidney diseases and cardiovascular diseases were adjusted using appropriate inflators such as price inflation to account for prices changes and population growth over the period to 2012. (b) The costs associated with chronic kidney disease relate to individuals with type 2 diabetes only.

Source: Access Economics (2005), Access Economics (2008a), Access Economics (2011), and Deloitte Access Economics' calculations.

Potential interventions to offset the burden of liver disease

Breakeven analyses were conducted to assess the effectiveness of two potential interventions aimed at reducing the cost of liver disease in Australia: first, a GESA-led education program to increase awareness of chronic liver diseases through collaboration with Medicare Locals and GESA/ALA; and second, a nurse-led community based care model, which is supported and linked to a hospital based liver centre, for liver diseases. A third cost effectiveness analysis was also performed on a primary liver cancer screening program to be aimed at high risk individuals.

For the first two interventions, costs of existing initiatives are not available so estimates were based on the costs of similar initiatives. The National Perinatal Depression Initiative and a nurse-led model of care for Parkinson disease were used, estimated to cost around \$6 million and \$7.5 million per annum according to the Western Australian Government Department of Health and Parkinson's Australia, respectively. The breakeven point at which the costs and benefits equate was for preventing 585 symptomatic cases in the education program, and for the nurse-led community care model the breakeven point was keeping 732 people with liver disease healthy enough that their productivity was on par with that of the general Australian population.

The primary liver cancer screening program was found to be highly cost effective among patients with cirrhosis and males with hepatitis B. The cost per life year gained was \$2,646 in 2012.

Recommendations

It is recommended that:

- a national database for sub entities of chronic liver disease is established;
- a pilot project is conducted through collaboration between a Medicare Local and GESA/ALA to establish a model liver clinic that delivers multidisciplinary care to patients with chronic liver disease – focussing on GP, patient and family education, treatment of the disease and prevention of progression, nutritional support to prevent complications related to over- or under-nutrition, social support, links to drug and alcohol services, and tele-health outreach;

- a pilot project is conducted through collaboration between GESA, the Gastroenterological Nurses' College of Australia and the Australasian Hepatology Association to establish a nurse-led community based model of care run from a hospital based liver centre; and
- a trial screening program – a six monthly alpha fetoprotein blood test and ultrasound – is introduced for the approximately 70,000 Australians who have liver cirrhosis or who are 40+ males with non-cirrhotic hepatitis B.

Deloitte Access Economics

1 Introduction

Deloitte Access Economics was commissioned by the Gastroenterological Society of Australia (GESA) and the Australian Liver Association (ALA) to estimate the economic costs and health burden of liver diseases in Australia. In conjunction with the contributions made by members of the ALA, this project was overseen by an expert reference group consisting of leading liver disease researchers and clinicians in Australia³.

1.1 Aim and deliverables

The objectives of this project were to:

- determine the economic impact of liver diseases in Australia;
- estimate the burden of disease of liver diseases in Australia; and
- model the potential impact of three intervention strategies.

1.2 Structure of this report

This report is structured as follows:

- Chapter 2 describes the prevalence and mortality of the most common liver diseases in Australia and provides prevalence estimates to 2030.
- Chapter 3 outlines the types and classification of costs considered in the analysis.
- Chapter 4 lists the health system costs of liver disease in Australia in 2012.
- Other financial costs are considering in Chapter 5 including productivity losses, carer costs and funeral costs.
- The burden of disease brought about by liver disease is estimated in Chapter 6.
- Chapter 7 investigates the effectiveness of three interventions (from an economic standpoint) aimed at reducing the burden of liver disease in Australia.

³ The expert panel includes Associate Professor Amany Zekry, Associate Professor Amanda Nicoll, Professor Geoffrey McCaughan, Dr Katherine Stuart, Associate Professor Leon Adam, Professor Matthew Law, Professor Paul Haber, and Professor William Sievert.

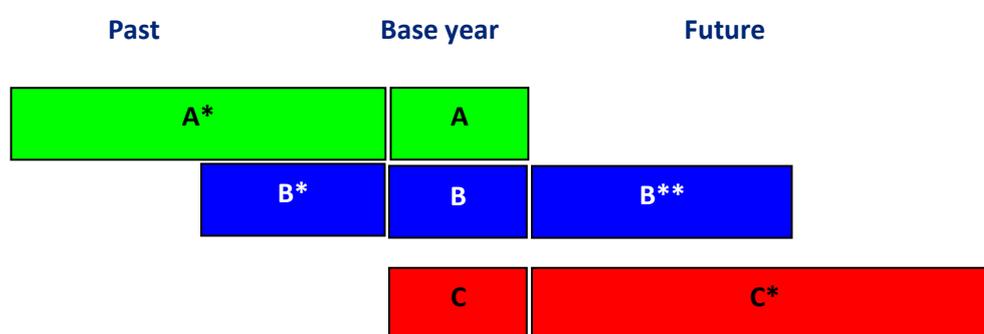
2 Prevalence and mortality

2.1 Methodology

2.1.1 Incidence versus prevalence approaches

This report utilises a **prevalence (annual costs) approach to estimating the costs of liver disease in Australia**. The alternative approach is an incidence (lifetime costs) approach. The difference between incidence and prevalence approaches is illustrated in the following diagram.

Figure 2.1: Incidence and prevalence approaches to measurement of annual costs



Annual prevalence costs in the base

$$\text{year} = \Sigma(A + B + C);$$

$$\text{Annual incidence costs in the base year} = \Sigma(C + \text{present value of } C^*)$$

Using an **incidence** approach, only cases like 'c' would be included, with the total cost estimate equivalent to the sum of all the costs in the base year (ΣC) plus the present value of all the future costs (ΣC^*). Costs associated with patients who were diagnosed with liver disease in an earlier year would be excluded.

Using a **prevalence** approach, costs in 2012 relating to *a*, *b* and *c* would all be included, with total costs equal to $\Sigma(A + B + C)$. Costs in all other years are excluded. However, for people who die in that year, the present value of future costs associated with their death (e.g. future lifetime earnings lost) is included using the prevalence approach.

Prevalence refers to the total number of people in a population with a condition at a given time. A **prevalence rate** expresses that number relative to the population total, which may vary by age-gender groups. Such data can be difficult to attain, particularly when prevalence is required by age and gender groups for conditions such as hepatitis or NAFLD which people may not know they have or may be disinclined to self-report. A multifaceted search approach is often required.

2.1.2 Approach

As a starting point, papers provided by GESA following the project inception meeting were reviewed. These papers lacked the necessary granularity for this initial and pivotal phase of the investigation, but provided useful aggregates for triangulation. A brief literature search

was next conducted and yielded both published papers and grey literature such as reports issued by Government agencies. Published references were largely unhelpful as these did not contain the age and gender detail needed for prevalence and mortality estimates. In the absence of local data, international papers were reviewed. Finally, a general internet search was undertaken; sites included the Department of Health and Ageing, AIHW, NSW Health and Victorian Department of Health. This step yielded some helpful hepatitis and primary liver cancer prevalence and mortality data, albeit not recent. Overall, data were scarce. Authors of published papers, the Kirby Institute, liver disease groups and GESA were contacted for assistance in retrieving outstanding necessary data.

2.1.3 Population data

To calculate the prevalence of each condition in 2012 and then make projections to 2030 it was necessary to utilise ABS population data. Series B population projections (generated from Census data) were used which reflect declining trend rates of mortality, a total fertility rate for Australia of 1.8 and life expectancy of 85 years and 88 years respectively for males and females in the base year (ABS 2008).

Using age and gender grouped demographic data means that the impact of future demographic ageing is incorporated in the future prevalence estimates (Section 0). We would recommend that any future projections are based on these relatively reliable data only, as there are a number of issues that work against trying to allow for other factors that may impact on age-specific prevalence rates.

- We cannot assume that because a risk factor (eg. obesity) has increased in the past, that it will continue to do so in the future, or at what rate. Moreover, studies on changes in risk factors (e.g. alcohol abuse) and other prevalence drivers can present varying results depending on methodologies, timeframes, populations and other factors taken into account in any standardisation. Significant literature review would be required (which would be quite costly). Assumptions would need to be made about the precise quantitative links between risk factors and prevalence, which can be arguable and detract from an overall conservative approach.
- Very often, it is not possible to make allowance for what may be the most important factors – e.g. new research that results in superior treatments, which may reduce prevalence rates. As with most other reputable forecasting bodies, we are not willing to predict the likelihood of such possible impacts on liver disease prevalence or costs.

The projections here are thus based on constant prevalence rates per age-gender cohort.

2.2 Viral hepatitis

2.2.1 Hepatitis A

2.2.1.1 Disease description, risk factors and treatment options

Hepatitis A is a virus that infects the liver. The majority of infected adults will feel unwell, lose their appetite, develop nausea and fatigue. Some people develop jaundice, a yellow tinge in the whites of the eyes and skin and their urine may become very dark. Rarely, people develop an intense itch.

Hepatitis A is spread from person to person, or through food contaminated with faeces that contain the hepatitis A virus. The diagnosis of hepatitis A can be achieved through a blood test whereby increased IgM antibodies imply current infection by hepatitis A and IgG antibodies are indicative of a past infection.

Currently, there is no specific treatment for hepatitis A. Most people feel unwell for a period of one to two weeks but gradually get better. It is rare that infected persons are hospitalised. In contrast to hepatitis B and C, hepatitis A does not result in chronic liver damage or cirrhosis of the liver. Moreover, a recovered person is immune to future infection with hepatitis A.

The people who are most at risk of hepatitis A infection are:

- people who travel to third world countries;
- child care workers;
- men who have sex with men;
- people who live in institutions;
- sewerage workers;
- health care workers; and
- Indigenous Australians.

There is a safe and effective vaccine available for hepatitis A.

2.2.1.2 Disease prevalence

Notifications data were used to estimate Hepatitis A, based on information assimilated by the Kirby Institute. Incidence data were used since duration is less than one year, so one-year prevalence would be identical to notifications. The average of notifications over the past five years was used as an estimate for 2012, since annual notifications vary and there is no clear trend. These prevalence estimates triangulated well with earlier prevalence estimates from the Victorian Government Department of Human Services (2005), which had been based on notifications to the Victorian Infectious Diseases Epidemiology and Surveillance System.⁴ Prevalence rates were applied to the 2012 Australian population projection (ABS 2008). The total estimate was for 284 people with Hepatitis A in 2012.

Table 2.1: Prevalence of hepatitis A in Australia, 2012

Age group	Males		Females		Total Cases
	Rate	Cases	Rate	Cases	
0-4	0.001%	9	0.001%	7	16
5-9	0.002%	12	0.001%	10	22
10-14	0.002%	12	0.001%	10	22
15-19	0.001%	11	0.001%	11	21
20-24	0.002%	18	0.002%	15	33
25-29	0.002%	18	0.002%	15	33
30-34	0.002%	13	0.001%	11	24

⁴ The Victorian Government Department of Human Services applied an upward adjustment, by a factor of five, to the number of notifications to account for under-reporting by clinicians.

35-39	0.002%	13	0.001%	11	24
40-44	0.001%	8	0.001%	9	17
45-49	0.001%	8	0.001%	8	16
50-54	0.001%	7	0.001%	7	14
55-59	0.001%	6	0.001%	6	13
60-64	0.001%	4	0.001%	4	8
65-69	0.001%	3	0.001%	3	6
70-74	0.001%	2	0.001%	2	5
75-79	0.001%	2	0.001%	2	4
80-84	0.001%	1	0.001%	2	3
85+	0.001%	1	0.001%	2	3
Total		148		135	284

Note: Total may not equal the sum of the parts due to rounding.

Source: Kirby Institute (2012), ABS (2008).

2.2.1.3 Disease mortality

Hepatitis A rarely causes death. Mortality rates for individuals with the condition are expected to be on par with the rest of the Australian population.

2.2.2 Hepatitis B

2.2.2.1 Disease description, risk factors and treatment options

Hepatitis B is a virus which brings about inflammation of the liver. The virus is transmitted through blood and other bodily fluids, including from mother to baby at birth, sexual transmission, through intravenous drug use and needle stick injuries. Healthcare workers and intravenous drugs users therefore have a higher chance of becoming hepatitis B positive. The disease affects more males than females and a younger population, below 30 years (Victorian Government Department of Human Services, 2005). It is also worth noting that chronic HBV is prevalent among migrants from countries where English is not their primary language with migrants from China and Vietnam taking the lead (Cowie, 2010). Infected individuals should avoid excess alcohol consumption and help prevent further disease transmission.

Hepatitis B can be diagnosed through blood tests which assess liver function and the presence of antigens. Liver scans and biopsies can also help determine the extent of liver damage caused by the disease.

Regular monitoring is required for patients infected with the virus and antiviral drugs may be prescribed to those who have liver damage. Chronic HBV related liver disease has a high risk of progressing to primary liver cancer, with approximately 15-25% of people with chronic HBV will develop cirrhosis during their lifetime (GESA, 2012a).

There is now a safe and effective hepatitis B vaccine which can provide immunity to the disease (prior to exposure) in most cases.

2.2.2.2 Disease prevalence

Prevalence rates for hepatitis B were based on an average of estimates from the Victorian Government Department of Human Services (2005) and Sullivan et al (2004). These were triangulated with data sourced through special request from the Western Australia Department of Health and notifications data from the Kirby Institute (2012). The latter estimated that there are approximately 7,000 new cases notified each year. The Kirby Institute (2012, Table 6.2.1) estimated that the plausible range of hepatitis B prevalence in 2011 was 184,000 to 241,000, with a point estimate of 209,000 in that year. These Kirby Institute estimates were based on data from the Hepatitis B Program, Epidemiology Unit, Victorian Infectious Diseases Reference Laboratory. The combined estimates of prevalence rates were applied to the 2012 Australian population projection (ABS 2008). The total estimate was for 211,089 people with hepatitis B in 2012.

Table 2.2: Prevalence of hepatitis B in Australia, 2012

Age group	Males		Females		Total Cases
	Rate	Cases	Rate	Cases	
0-4	0.167%	1,237	0.154%	1,087	2,325
5-9	0.167%	1,193	0.154%	1,049	2,241
10-14	0.379%	2,725	0.366%	2,509	5,234
15-19	0.863%	6,587	0.848%	6,142	12,729
20-24	1.500%	12,275	1.484%	11,524	23,799
25-29	1.500%	12,406	1.484%	11,962	24,368
30-34	0.227%	1,781	0.211%	1,640	3,421
35-39	0.246%	1,903	0.225%	1,755	3,658
40-44	1.890%	15,223	1.869%	15,266	30,489
45-49	1.890%	14,509	1.869%	14,561	29,070
50-54	1.148%	8,623	1.127%	8,680	17,303
55-59	1.134%	7,708	1.121%	7,793	15,501
60-64	0.922%	5,692	0.909%	5,719	11,411
65-69	0.922%	4,704	0.909%	4,721	9,425
70-74	0.922%	3,406	0.909%	3,550	6,957
75-79	0.899%	2,428	0.895%	2,762	5,190
80-84	0.899%	1,763	0.895%	2,271	4,034
85+	0.899%	1,393	0.895%	2,541	3,935
Total		105,555		105,535	211,089

Note: Total may not equal the sum of the parts due to rounding.

Sources: Kirby Institute (2012), Victorian Government Department of Human Services (2005), Sullivan et al (2004), Western Australia Department of Health (special request data, November 2012), ABS (2008).

2.2.2.3 Disease mortality

Mortality rates were also derived from a range of sources. The Kirby Institute (2012) estimated that there were 382 (294 to 621) deaths attributable to chronic hepatitis B infection in 2011 (also based on the Hepatitis B Program, Epidemiology Unit, Victorian Infectious Diseases Reference Laboratory). Age and gender distributions of prevalence

were based on triangulation of Walter et al (2011), Amin et al (2006), Western Australia Department of Health and Victorian Government Department of Human Services (2005) data. There were an estimated 385 deaths from hepatitis B in 2012.

Table 2.3: Mortality of hepatitis B in Australia, 2012

Age group	Males Rate	Deaths	Females Rate	Deaths	Total Deaths
0-4	0.000%	0	0.000%	0	1
5-9	0.000%	0	0.000%	0	1
10-14	0.000%	1	0.000%	1	1
15-19	0.000%	2	0.000%	1	3
20-24	0.000%	3	0.000%	3	6
25-29	0.000%	2	0.000%	2	3
30-34	0.000%	0	0.000%	0	0
35-39	0.000%	0	0.000%	0	1
40-44	0.001%	9	0.001%	9	18
45-49	0.002%	12	0.002%	12	24
50-54	0.001%	9	0.001%	9	19
55-59	0.003%	20	0.003%	20	40
60-64	0.004%	22	0.003%	22	44
65-69	0.006%	28	0.005%	28	57
70-74	0.004%	16	0.004%	17	34
75-79	0.008%	20	0.008%	23	44
80-84	0.015%	29	0.015%	38	67
85+	0.006%	9	0.006%	16	24
Total		183		202	386

Note: Total may not equal the sum of the parts due to rounding.

Source: Kirby Institute (2012), Victorian Government Department of Human Services (2005), Walter et al (2011), Amin et al (2006), Western Australia Department of Health (special request data, November 2012), ABS (2008).

2.2.3 Hepatitis C

The hepatitis C virus is the most common cause of hepatitis, or liver inflammation, in Australia (GESA 2012). Most people become infected with hepatitis C are intravenous drug users who have been exposed to infected blood, for example, through the sharing of needles. In the past some blood transfusions were contaminated with the virus, although all blood is now screened and infection this way is very rare.

In the first stage of the disease patients are often asymptomatic; a diagnosis of hepatitis C can be achieved through an antibody blood test. There are many different hepatitis C viruses and further tests can determine the type of hepatitis C infection which can in turn dictate the most appropriate treatment for the patient. Treatment often involves interferon injections and oral antiviral drugs (GESA 2012). Liver transplantation is needed in a minority of cases and is considered fairly rare.

Of people infected with hepatitis C, Hepatitis Australia estimates that about 25% will clear the virus completely within two to six months, and will have antibodies. About 75% will develop ongoing (or chronic) infection although nearly one third of these will be asymptomatic (but still able to transmit the virus). After an average of 15 years, more than 50%-80% of those with chronic hepatitis C will experience some symptoms and develop some liver damage.⁵

About 7-20% of people with hepatitis C develop cirrhosis (GESA 2012), high risk factors include being infected at an older age, excessive alcohol consumption, concomitant hepatitis B infection, and being overweight or diabetic.

2.2.3.1 Disease prevalence

Published papers related to hepatitis C were retrieved during the literature search; however, none outlined Australian prevalence and mortality data by age and gender. Hence, advice from the GESA expert reference group, the Kirby Institute, the Victorian Government Department of Human Services (2005), and special request data from the Western Australia Department of Health were again used and triangulated with earlier information from the Australian Hepatitis Council (2002). The latter source estimated a prevalence of Hepatitis C of 210,000 people in 2002. The Hepatitis C Sub-Committee of the Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis (2006) estimated around 264,000 people living with HCV antibodies in Australia in 2005. Our estimate of prevalence of hepatitis C in 2012 was 307,040 people based on the combined sources.

Table 2.4: Prevalence of hepatitis C in Australia, 2012

Age group	Males		Females		Total Cases
	Rate	Cases	Rate	Cases	
0-4	0.017%	125	0.005%	38	163
5-9	0.017%	121	0.005%	37	157
10-14	0.017%	121	0.005%	37	158
15-19	0.631%	4,816	0.432%	3,129	7,946
20-24	0.631%	5,167	0.432%	3,354	8,521
25-29	0.631%	5,222	0.432%	3,481	8,704
30-34	0.631%	4,954	0.432%	3,350	8,304
35-39	2.329%	18,015	1.489%	11,603	29,618
40-44	2.329%	18,762	1.489%	12,159	30,922
45-49	2.329%	17,882	1.489%	11,598	29,480
50-54	2.329%	17,504	1.489%	11,469	28,974
55-59	3.249%	22,084	1.942%	13,497	35,581
60-64	3.249%	20,062	1.942%	12,215	32,277
65-69	3.249%	16,580	1.942%	10,085	26,664
70-74	3.249%	12,005	1.942%	7,583	19,589
75-79	3.551%	9,586	2.120%	6,540	16,127
80-84	3.551%	6,959	2.120%	5,378	12,337

⁵ <http://www.hepatitisaustralia.com/about-hepatitis/hepatitis-c>

85+	3.551%	5,501	2.120%	6,017	11,518
Total		185,468		121,572	307,040

Note: Total may not equal the sum of the parts due to rounding.

Source: Kirby Institute (2012), Victorian Government Department of Human Services (2005), Australian Hepatitis Council (2002), Western Australia Department of Health (special request data, November 2012), ABS (2008).

2.2.3.2 Disease mortality

Similar sources to those listed above were used for hepatitis C mortality estimates (see note to Table 2.5). There were an estimated 2,550 deaths from hepatitis C in 2012.

Table 2.5: Mortality of hepatitis C in Australia, 2012

Age group	Males		Females		Total Deaths
	Rate	Deaths	Rate	Deaths	
0-4	0.000%	0	0.000%	0	0
5-9	0.000%	0	0.000%	0	0
10-14	0.000%	0	0.000%	0	0
15-19	0.000%	0	0.000%	0	0
20-24	0.000%	0	0.000%	0	0
25-29	0.000%	0	0.000%	0	0
30-34	0.000%	0	0.000%	0	0
35-39	0.017%	135	0.004%	29	164
40-44	0.017%	141	0.004%	30	171
45-49	0.017%	134	0.004%	29	163
50-54	0.017%	131	0.004%	28	159
55-59	0.058%	395	0.013%	87	482
60-64	0.058%	359	0.013%	79	438
65-69	0.058%	297	0.013%	65	362
70-74	0.058%	215	0.013%	49	264
75-79	0.028%	74	0.021%	65	139
80-84	0.028%	54	0.021%	53	107
85+	0.028%	43	0.021%	59	102
Total		1,977		573	2,550

Note: Total may not equal the sum of the parts due to rounding.

Source: Kirby Institute (2012), Victorian Government Department of Human Services (2005), Australian Hepatitis Council (2002), Walter et al (2011), Amin et al (2006), Western Australia Department of Health (special request data, November 2012), ABS (2008).

2.3 Non-alcoholic fatty liver disease

2.3.1.1 Disease description, risk factors and treatment options

Non-alcoholic fatty liver disease (NAFLD) is the most common cause of mildly abnormal liver test results and is typified by the accumulation of fat in the liver cells (GESA 2011). Major risk factors are obesity, high cholesterol, and type 2 diabetes. Often there are no symptoms of the condition, although fatigue, abdominal pain and weight loss occur.

The condition is diagnosed through liver blood tests and requires imaging such as an ultrasound of the liver to detect excess fat. There is no drug treatment of NAFLD, although lifestyle modifications can assist greatly, such as weight loss through dietary changes and exercise and reduced alcohol consumption. Severe NAFLD can progress to cirrhosis and liver failure (Adams et al, 2009).

2.3.1.2 Disease prevalence

Estimating the prevalence of NAFLD is difficult, partly because the disease encompasses a spectrum of abnormalities from irregular liver enzymes (detected through a blood test) to steatohepatitis (as seen on a liver biopsy). Different diagnostic approaches inevitably bring about varied prevalence estimates.

Gan et al (2011) referenced local and international data to estimate the prevalence of NAFLD by age group. The authors, however, did not provide specific prevalence rates for individuals aged 50 years and over aside from approximating *over 40%* for those aged 70 years and above. Deloitte Access Economics thus applied a prevalence rate of 40% to all individuals aged 50 years and above. No specific gender rates were provided and so prevalence rates by age group were applied to both females and males. The total estimate was for 5,538,677 people with NAFLD in 2012.

Table 2.6: Prevalence of NAFLD in Australia, 2012

Age group	Males		Females		Total Cases
	Rate	Cases	Rate	Cases	
0-4	2%	14,863	2%	14,111	28,973
5-9	2%	14,327	2%	13,607	27,934
10-14	5%	35,980	5%	34,252	70,232
15-19	5%	38,150	5%	36,226	74,376
20-24	18%	147,326	18%	139,773	287,099
25-29	18%	148,907	18%	145,086	293,993
30-34	18%	141,256	18%	139,624	280,880
35-39	18%	139,205	18%	140,284	279,489
40-44	39%	314,120	39%	318,531	632,651
45-49	39%	299,391	39%	303,821	603,212
50-54	40%	300,572	40%	308,160	608,732
55-59	40%	271,926	40%	277,952	549,878
60-64	40%	247,028	40%	251,557	498,586
65-69	40%	204,149	40%	207,677	411,826
70-74	40%	147,827	40%	156,172	303,999
75-79	40%	107,982	40%	123,429	231,411
80-84	40%	78,393	40%	101,495	179,888
85+	40%	61,969	40%	113,550	175,519
Total		2,713,372		2,825,305	5,538,677

Note: Total may not equal the sum of the parts due to rounding.

Source: Gan et al (2011)

2.3.1.3 Disease mortality

Adam and Lindor (2007) found NAFLD (in the US) to be associated with a standardised mortality ratio 1.34 (based on a large population cohort study) and the main risk factors for death were diabetes and cirrhosis. The GESA expert reference group deemed this mortality ratio to be significantly higher than that observed in the Australian population and Ong et al (2008) was suggested. This paper found NAFLD patients had a slightly higher mortality rate (hazard ratio of 1.038) than the general population. To estimate the number of deaths in Australia from NAFLD, 2010 (most recent) Australian age and gender specific death rates per 1,000 population (ABS 2012) were inflated by 0.038 (the excess mortality rate) and then multiplied by the prevalence rate of NAFLD and the expected 2012 population (ABS 2008). There were an estimated 2,264 deaths from NAFLD in 2012.

Table 2.7: Mortality of NAFLD in Australia, 2012

Age group	Males Rate	Deaths	Females Rate	Deaths	Total Deaths
0-4 ⁶	0.00%	0	0.00%	0	0
5-9	0.00%	0	0.00%	0	0
10-14	0.00%	0	0.00%	0	0
15-19	0.00%	1	0.00%	0	1
20-24	0.00%	3	0.00%	2	5
25-29	0.00%	4	0.00%	2	6
30-34	0.00%	5	0.00%	2	7
35-39	0.00%	6	0.00%	3	10
40-44	0.00%	19	0.00%	11	30
45-49	0.00%	27	0.00%	16	43
50-54	0.01%	39	0.00%	25	63
55-59	0.01%	54	0.00%	33	86
60-64	0.01%	73	0.01%	45	118
65-69	0.02%	102	0.01%	59	161
70-74	0.03%	122	0.02%	79	201
75-79	0.06%	152	0.04%	109	261
80-84	0.10%	201	0.07%	177	378
85+	0.22%	345	0.19%	548	893
Total		1,154		1,110	2,264

Note: Total may not equal the sum of the parts due to rounding.

Source: Ong et al (2008), ABS (2012).

⁶ Age-specific death rate of 1-4 years used (ABS 2012) for 0-4 age group

2.4 Hepatocellular carcinoma

2.4.1.1 Disease description, risk factors and treatment options

Primary liver cancer, or hepatocellular carcinoma, arises in the liver cells (hepatocytes) and is less common than metastatic or secondary liver cancer, which originates from other organs in the body. Symptoms of primary liver cancer can be non-specific, or common with other diagnoses such as abdominal or back pain, weight loss, jaundice and tiredness. Treatment can include surgery, radiotherapy and chemotherapy.

Amin et al (2007) found the incidence of hepatocellular carcinoma, or primary liver cancer, was linked to a person's country of birth. For example, individuals born in Vietnam had a relative risk of 11 for the disease compared with Australian born people. About 30% of cases were linked to hepatitis B and/or C infection; another risk factor is liver cirrhosis.

2.4.1.2 Disease prevalence

National, state and territory cancer registries such as the Australian Cancer Database and the Victorian Cancer Registry record the incidence of various types of cancers in a given year. The Australian Institute of Health and Welfare (AIHW 2011) compiles this data into the Australian Cancer Incidence and Mortality books. Primary liver cancer prevalence and mortality estimates have been based on this dataset⁷. The total number of cases of primary liver cancer was estimated as 1,451 in 2012.

Table 2.8: Prevalence of primary liver cancer in Australia, 2012

Age group	Males		Females		Total Cases
	Rate	Cases	Rate	Cases	
0-4	0.001%	4	0.001%	6	11
5-9	0.000%	0	0.000%	1	1
10-14	0.000%	0	0.000%	0	0
15-19	0.000%	2	0.000%	1	3
20-24	0.000%	2	0.001%	4	6
25-29	0.000%	2	0.000%	2	4
30-34	0.001%	4	0.000%	1	5
35-39	0.002%	12	0.001%	6	17
40-44	0.002%	15	0.001%	6	21
45-49	0.006%	49	0.002%	14	63
50-54	0.016%	117	0.003%	24	141
55-59	0.018%	121	0.003%	20	142
60-64	0.019%	116	0.007%	45	161
65-69	0.029%	150	0.010%	51	201
70-74	0.037%	135	0.013%	51	186
75-79	0.052%	140	0.017%	52	192

⁷ The AIHW publishes incidence rates. These rates were used to estimate the prevalence of disease as average survival is expected to be below one year.

80-84	0.054%	107	0.020%	52	158
85+	0.057%	88	0.018%	51	139
Total		1,064		387	1,451

Note: Total may not equal the sum of the parts due to rounding.
Source: AIHW (2011), ABS (2008)

2.4.1.3 Disease mortality

Population mortality rates were also sourced from AIHW (2011). The total number of deaths from primary liver cancer was estimated as 1,270 in 2012.

Table 2.9: Mortality of primary liver cancer in Australia, 2012

Age group	Males		Females		Total Deaths
	Rate	Deaths	Rate	Deaths	
0-4	0.000%	0	0.000%	0	0
5-9	0.000%	0	0.000%	0	0
10-14	0.000%	1	0.000%	0	1
15-19	0.000%	0	0.000%	0	0
20-24	0.000%	0	0.000%	1	1
25-29	0.000%	2	0.000%	2	4
30-34	0.000%	3	0.000%	1	4
35-39	0.001%	7	0.000%	1	8
40-44	0.001%	11	0.001%	6	17
45-49	0.005%	41	0.001%	11	52
50-54	0.010%	73	0.002%	15	89
55-59	0.011%	76	0.003%	23	99
60-64	0.016%	97	0.007%	41	139
65-69	0.022%	110	0.009%	45	154
70-74	0.030%	110	0.018%	71	181
75-79	0.044%	118	0.019%	58	176
80-84	0.050%	98	0.030%	75	173
85+	0.050%	77	0.033%	94	171
Total		824		445	1,270

Note: Total may not equal the sum of the parts due to rounding.
Source: AIHW (2011), ABS (2008)

2.5 Alcohol related liver disease

2.5.1.1 Disease description, risk factors and treatment options

According to the National Health and Medical Research Council (2009), drinking no more than two standard drinks on any day reduces the lifetime risk of alcohol-related of harm for men and women. Chronic consumption of higher levels of alcohol can result in alcoholic liver disease (ALD), characterised by steatosis, fibrosis, cirrhosis and alcoholic hepatitis (Liang et al 2011). ALD is the main cause of death from long-term alcohol abuse.

Abstinence can significantly halt the progression of the disease. Treatment also involves correcting malnutrition and resolution of associated complications such as variceal haemorrhage, ascites and neuropsychiatric complications (Duggan and Duggan 2011).

2.5.1.2 Disease prevalence

Estimating the prevalence of ALD is difficult as most cases remain undetected during the early stages of the disease, before complications become pronounced (Duggan and Duggan 2011). The prevalence of ALD was calculated by combining information from the British Association for the Study of the Liver and British Society of Gastroenterology (2009) on Kaplan Meier survival rates for alcoholic liver disease, which showed average survival of eight (7.95) years from onset, the mortality calculations from the next section, rates of long term risky drinking in Australia from the latest Australian Health Survey (ABS, 2012g), and an assumption that there is a 15-year delay between commencement of risky drinking and onset of ALD⁸. In this way we estimated there were 6,203 cases of ALD in Australia in 2012.

Table 2.10: Prevalence of ALD in Australia, 2012

Age group	Males		Females		Total Cases
	Rate	Cases	Rate	Cases	
0-4	0.00%	0	0.00%	0	0
5-9	0.00%	0	0.00%	0	0
10-14	0.00%	0	0.00%	0	0
15-19	0.02%	0	0.01%	0	0
20-24	0.05%	0	0.02%	0	0
25-29	0.05%	0	0.02%	0	0
30-34	0.05%	176	0.02%	57	232
35-39	0.06%	373	0.02%	119	492
40-44	0.06%	440	0.02%	130	570
45-49	0.05%	417	0.02%	126	543
50-54	0.05%	466	0.02%	147	613
55-59	0.06%	486	0.02%	154	640
60-64	0.06%	396	0.02%	159	555
65-69	0.05%	388	0.02%	158	545
70-74	0.05%	434	0.02%	157	591
75-79	0.03%	394	0.01%	142	537
80-84	0.03%	257	0.01%	82	339
85+	0.03%	378	0.01%	167	545
Total		4,605		1,598	6,203

Note: Total may not equal the sum of the parts due to rounding.

Source: British Association for the Study of the Liver and British Society of Gastroenterology (2009), ABS (2012g), mortality estimates from next section, ABS (2012b).

⁸ Based on <http://www.drinkaware.co.uk/facts/factsheets/alcohol-and-your-liver> and <http://s3.gi.org/patients/cgp/pdf/alcohol.pdf>.

2.5.1.3 Disease mortality

In 2010 there were 751 ALD related deaths in Australia (ABS 2012b), 558 males and 193 females. The age distribution of deaths occurring due to ALD was sourced from the Australian Institute of Health and Welfare (2010). This reference presented data by gender in only two age groups, 35 to 54 years and 55 to 74 years. Mortality rates were calculated and applied to the 2012 Australian population projection (ABS 2008) to estimate the number of deaths this year from ALD. There were an estimated 780 deaths from ALD in 2012.

Table 2.11: Mortality of ALD in Australia, 2012

Age group	Males Rate	Deaths	Females Rate	Deaths	Total Deaths
0-4	0.000%	0	0.000%	0	0
5-9	0.000%	0	0.000%	0	0
10-14	0.000%	0	0.000%	0	0
15-19	0.000%	0	0.000%	0	0
20-24	0.000%	0	0.000%	0	0
25-29	0.000%	0	0.000%	0	0
30-34	0.000%	0	0.000%	0	0
35-39	0.008%	59	0.003%	25	84
40-44	0.008%	61	0.003%	26	88
45-49	0.008%	58	0.003%	25	83
50-54	0.008%	57	0.003%	25	82
55-59	0.016%	107	0.004%	31	138
60-64	0.016%	97	0.004%	28	126
65-69	0.016%	81	0.004%	23	104
70-74	0.016%	58	0.004%	17	76
75-79	0.000%	0	0.000%	0	0
80-84	0.000%	0	0.000%	0	0
85+	0.000%	0	0.000%	0	0
Total		579		201	780

Note: Total may not equal the sum of the parts due to rounding.

Source: ABS (2012b), AIHW (2010)

2.6 Cholestatic liver disease

2.6.1.1 Disease description, risk factors and treatment options

Primary biliary cirrhosis (PBC) and primary sclerosing cholangitis (PSC) are autoimmune and cholestatic liver diseases of unknown cause. PBC leads to the destruction of bile ducts and is much more prevalent in women (90% cases) than men (Kumagi T and Heathcote J 2008). Initial symptoms include itching, fatigue and jaundice. Vitamin A, D and E deficiencies often occur in the later stages of the disease. A diagnosis can be made through blood tests and a liver biopsy. Ursodeoxycholic acid is given to reduce gall stones; immunosuppressants may also be used (Kumagi T and Heathcote J 2008). PBC can require a liver transplant.

PSC is an uncommon condition which is typified by inflammation of the bile ducts followed by hardening and scarring. This can cause liver failure unless a transplant is performed. Over time the incidence of PSC has risen and the condition expressed more commonly in males (Card et al 2008).

2.6.1.2 Disease prevalence of primary biliary cirrhosis

Watson et al (1995) estimated a prevalence rate of PBC in Victoria of 19.1 per million population, based on a survey of physicians and reviews of hospital records. This rate, which differs across ethnicities, is substantially lower than that reported in the UK and Northern European populations. Prevalence by age was provided by Watson et al (1995) only for Australian born women. It was assumed that the condition does not affect persons below 35 years of age (Watson et al 1995, Kumagi and Heathcote 2008). Male prevalence rates were estimated to be one ninth of the female rates, with 433 cases in total in 2012.

Table 2.12: Prevalence of primary biliary cirrhosis in Australia, 2012

Age group	Males Rate	Cases	Females Rate	Cases	Total Cases
0-4	0.000%	0	0.000%	0	0
5-9	0.000%	0	0.000%	0	0
10-14	0.000%	0	0.000%	0	0
15-19	0.000%	0	0.000%	0	0
20-24	0.000%	0	0.000%	0	0
25-29	0.000%	0	0.000%	0	0
30-34	0.000%	0	0.000%	0	0
35-39	0.0004%	3	0.003%	27	30
40-44	0.0004%	3	0.003%	28	31
45-49	0.0004%	3	0.003%	26	29
50-54	0.0004%	3	0.003%	26	29
55-59	0.0010%	7	0.008%	59	65
60-64	0.0010%	6	0.008%	53	59
65-69	0.0013%	6	0.010%	50	56
70-74	0.0013%	5	0.010%	38	42
75-79	0.0013%	3	0.010%	30	33
80-84	0.0013%	2	0.010%	24	27
85+	0.0013%	2	0.010%	27	29
Total		43		389	433

Note: Total may not equal the sum of the parts due to rounding.

Source: Watson et al (1995), ABS (2008)

2.6.1.3 Disease mortality

Research indicated mortality rates are on par with those of the general population and this was verified by the GESA expert reference group.

2.6.1.4 Disease prevalence of primary sclerosing cholangitis

There is little published data available concerning PSC owing to the low incidence of the disease. Card et al (2008) studied a UK cohort of 223 with PSC. A prevalence rate of 3.85 per 100,000 was reported (in 2001) and 64% of patients were male. In the absence of more recent local studies, this rate was applied to the 2012 Australian population, taking into consideration the age and gender distribution in Card et al (2008). Most cases occurred in males aged 35 years and above, with a total of 872 cases in total across both males and females.

Table 2.13: Prevalence of primary sclerosing cholangitis in Australia, 2012

Age group	Males Rate	Cases	Females Rate	Cases	Total Cases
0-4	0.00%	4	0.00%	2	6
5-9	0.00%	4	0.00%	2	6
10-14	0.00%	4	0.00%	2	6
15-19	0.00%	10	0.00%	6	16
20-24	0.00%	10	0.00%	6	16
25-29	0.00%	25	0.00%	14	39
30-34	0.00%	25	0.00%	14	39
35-39	0.01%	45	0.00%	26	70
40-44	0.01%	45	0.00%	26	70
45-49	0.01%	53	0.00%	31	84
50-54	0.01%	53	0.00%	31	84
55-59	0.01%	57	0.00%	33	90
60-64	0.01%	57	0.01%	33	90
65-69	0.01%	56	0.01%	32	88
70-74	0.02%	56	0.01%	32	88
75-79	0.01%	24	0.00%	14	37
80-84	0.01%	24	0.01%	14	37
85+	0.00%	3	0.00%	2	4
Total		554		318	872

Note: Total may not equal the sum of the parts due to rounding.

Source: Card et al (2008), ABS (2008)

2.6.1.5 Disease mortality of primary sclerosing cholangitis

The mortality rate of PSC is significantly greater than that of the general population. Card et al (2008) reported a three-fold overall mortality rate increase (hazard ratio of 2.92). Patients also had a 40 fold increase in the risk of primary liver cancer.

To estimate the number of deaths in Australia from PSC, Australian age and gender specific death rates per 1,000 population (ABS 2012) were inflated by 1.92 (the excess mortality rate) and then multiplied by the prevalence rate of PSC and the 2012 population (ABS 2008). There were an estimated 16 deaths from PSC in total in 2012.

Table 2.14: Mortality of primary sclerosing cholangitis in Australia, 2012

Age group	Males Rate	Deaths	Females Rate	Deaths	Total Deaths
0-4	0.0000%	0	0.0000%	0	0
5-9	0.0000%	0	0.0000%	0	0
10-14	0.0000%	0	0.0000%	0	0
15-19	0.0000%	0	0.0000%	0	0
20-24	0.0000%	0	0.0000%	0	0
25-29	0.0000%	0	0.0000%	0	0
30-34	0.0000%	0	0.0000%	0	0
35-39	0.0000%	0	0.0000%	0	0
40-44	0.0000%	0	0.0000%	0	0
45-49	0.0000%	0	0.0000%	0	0
50-54	0.0000%	0	0.0000%	0	0
55-59	0.0001%	1	0.0000%	0	1
60-64	0.0001%	1	0.0000%	0	1
65-69	0.0003%	1	0.0001%	0	2
70-74	0.0006%	2	0.0002%	1	3
75-79	0.0006%	2	0.0002%	1	2
80-84	0.0016%	3	0.0005%	1	4
85+	0.0005%	1	0.0001%	0	1
Total		12		4	16

Note: Total may not equal the sum of the parts due to rounding.

Source: Card et al (2008), ABS (2010)

2.7 Haemochromatosis

2.7.1.1 Disease description, risk factors and treatment options

Haemochromatosis is a common genetic disorder where higher than normal amounts of iron are absorbed into the body. This can cause a build up of iron in certain organs such as the liver and heart, joints and glands also suffer. This damage may become permanent if diagnosed late in the course of the disease (GESA 2011a).

The disease occurs when two haemochromatosis genes are inherited and the diagnosis can be confirmed through a blood test. Ongoing monitoring is needed to check iron levels as the disease may not begin displaying symptoms until adulthood. If excess iron is detected, blood is removed from the body which stimulates more blood to be made, using up iron in the process. This process is repeated frequently at first and then three or four times a year for life (GESA 2011a).

The removal of excess iron can prevent or halt the damage to organs such as the liver. If a haemochromatosis patient commences early treatment and does not have liver cirrhosis, their life expectancy is normal (Genetics in Family Medicine 2007).

2.7.1.2 Disease prevalence

The prevalence of haemochromatosis is roughly one in 200 Australians of Caucasian descent⁹ (Barlow-Stewart 2007). The ABS does not report the proportion of Caucasian versus non-Caucasian Australians, although it is estimated that over 90% of the population is deemed Caucasian or white.¹⁰ A prevalence rate of 0.5% was therefore applied to the entire Australian population. Gender differences were not observed in the reviewed literature, nor a difference in prevalence across age groups. There were a total of 113,237 cases in total estimated for 2012.

Table 2.15: Prevalence of haemochromatosis in Australia, 2012

Age group	Males Rate	Cases	Females Rate	Cases	Total Cases
0-4	0.500%	3,716	0.500%	3,528	7,243
5-9	0.500%	3,582	0.500%	3,402	6,984
10-14	0.500%	3,598	0.500%	3,425	7,023
15-19	0.500%	3,815	0.500%	3,623	7,438
20-24	0.500%	4,092	0.500%	3,883	7,975
25-29	0.500%	4,136	0.500%	4,030	8,166
30-34	0.500%	3,924	0.500%	3,878	7,802
35-39	0.500%	3,867	0.500%	3,897	7,764
40-44	0.500%	4,027	0.500%	4,084	8,111
45-49	0.500%	3,838	0.500%	3,895	7,733
50-54	0.500%	3,757	0.500%	3,852	7,609
55-59	0.500%	3,399	0.500%	3,474	6,873
60-64	0.500%	3,088	0.500%	3,144	6,232
65-69	0.500%	2,552	0.500%	2,596	5,148
70-74	0.500%	1,848	0.500%	1,952	3,800
75-79	0.500%	1,350	0.500%	1,543	2,893
80-84	0.500%	980	0.500%	1,269	2,249
85+	0.500%	775	0.500%	1,419	2,194
Total		56,343		56,894	113,237

Note: Total may not equal the sum of the parts due to rounding.

Source: Barlow-Stewart K (2007), ABS (2008)

2.7.1.3 Disease mortality

If a haemochromatosis patient commences early treatment and does not have liver cirrhosis, their life expectancy is normal (Genetics in Family Medicine 2007). Expert opinion indicated that mortality rates attributed to haemochromatosis that has been treated are on par with those of the general population.

⁹ <http://www.mcri.edu.au/research/research-projects/mi-iron-study/what-is-haemochromatosis.aspx>

¹⁰ http://www.indexmundi.com/australia/demographics_profile.html

2.8 Paediatric liver disease

2.8.1.1 Disease description, risk factors and treatment options

In addition to the liver diseases outlined above, paediatric patients may also be inflicted with neonatal hepatitis and biliary atresia. Approximately 15 to 20 Australian children each year are born with biliary atresia, an aggressive liver disease responsible for 60% of all paediatric liver transplants¹¹.

2.8.1.2 Disease prevalence

Given the low number of paediatric patients with liver diseases other than those described in Sections 2.2.1 to 2.7 above, the prevalence of paediatric liver disease was estimated by summing these diseases only. Paediatric cases have been included in the population case estimates and number of deaths stated in the above sections. There were a total of 261,288 cases of liver disease in Australians aged under 19 years.

Table 2.16: Prevalence of paediatric liver disease in Australia, 2012

Age group	Male Cases	Female Cases	Total Cases
0-4	19,958	18,780	38,738
5-9	19,239	18,107	37,346
10-14	42,441	40,235	82,676
15-19	53,391	49,138	102,529
Total	135,028	126,260	261,288

Note: Total may not equal sum of parts due to rounding

2.8.1.3 Disease mortality

Mortality was likewise estimated by summing the disease components described above. There were an estimated 8 deaths estimated from liver disease for Australian children aged under 19 years.

Table 2.17: Mortality of paediatric liver disease in Australia, 2012

Age group	Male Deaths	Female Deaths	Total Deaths
0-4	0	0	1
5-9	0	0	1
10-14	2	1	3
15-19	2	2	4
Total	4	3	8

Note: Total may not equal the sum of the parts due to rounding.

¹¹ http://www.liver.org.au/liver_diseases.htm

2.9 Overall liver disease in Australia

2.9.1.1 Disease prevalence

The overall prevalence of liver disease in Australia in 2012¹² was calculated by summing the individual prevalence estimates associated with each of the seven disease subtypes above. It is likely that some individuals will suffer from more than one liver disease, for example, have co-infection with hepatitis B and C, which may also lead to primary liver cancer (Crockett S and Keeffe E 2005). The resulting over estimation is offset by the exclusion of other liver diseases in Australia (such as drug induced hepatitis, autoimmune hepatitis, and fulminant liver failure), as well as potential under-diagnosis which arises in part due to the asymptomatic nature of many disease subtypes, as described above (e.g. early stage ALD). There were an estimated 6.2 million cases of hepatitis (A, B, C), NAFLD, ALD, primary liver cancer, PBC, PSC and haemochromatosis in 2012.

Table 2.18: Overall prevalence of liver disease in Australia, 2012

Age group	Male Cases	Female Cases	Total Cases
0-4	19,958	18,780	38,738
5-9	19,239	18,107	37,346
10-14	42,441	40,235	82,676
15-19	53,391	49,138	102,529
20-24	168,889	158,558	327,448
25-29	170,717	164,592	335,309
30-34	152,133	148,576	300,708
35-39	163,436	157,727	321,162
40-44	352,643	350,240	702,883
45-49	336,151	334,079	670,231
50-54	331,104	332,396	663,499
55-59	305,794	302,988	608,782
60-64	276,448	272,930	549,378
65-69	228,587	225,373	453,959
70-74	165,719	169,538	335,257
75-79	121,909	134,513	256,422
80-84	88,486	110,587	199,072
85+	70,110	123,776	193,886
Total	3,067,153	3,112,133	6,179,287

Note: Total may not equal the sum of parts due to rounding.

¹² Note that auto immune hepatitis was not considered due to lack of data.

2.9.1.2 Disease mortality

Mortality attributed to all major liver diseases was likewise estimated by combining the estimates provided in Sections 2.2.1 to 2.7 above, totalling 7,264 (not accounting for comorbidity). Because a person cannot die twice, in estimating productivity costs and burden of disease, comorbidity is taken into account (see later chapters).

Table 2.19: Overall mortality of liver disease in Australia, 2012

Age group	Male Deaths	Female Deaths	Total Deaths
0-4	0	0	1
5-9	0	0	1
10-14	2	1	3
15-19	2	2	4
20-24	6	5	12
25-29	8	5	13
30-34	8	3	12
35-39	208	58	266
40-44	241	83	324
45-49	272	93	365
50-54	310	103	412
55-59	653	195	848
60-64	650	216	865
65-69	618	221	839
70-74	525	234	759
75-79	366	255	621
80-84	385	344	729
85+	473	718	1,192
Total	4,729	2,535	7,266

Note: Total may not equal the sum of the parts due to rounding.

2.10 Extrapolation to 2030

As discussed, demographic ageing is incorporated in the future prevalence estimates (ABS 2008), with the change in the incidence of risk factors or development of superior treatments not possible to predict. We thus allow for projections based on constant prevalence rates per age-gender cohort. As such, the number of cases of liver disease is projected to increase to over 8 million by 2030.

Table 2.20: Prevalence of liver disease in Australia, 2030

Disease subtype	Male Cases	Female Cases	Total Cases
Hepatitis A	180	164	344
Hepatitis B	131,782	131,061	262,843
Hepatitis C	251,391	162,887	414,278
Non-alcoholic fatty liver disease	3,566,969	3,693,619	7,260,588
Primary liver cancer	1,652	601	2,253
Alcoholic liver disease	5,816	2,008	7,824
Primary biliary cirrhosis	63	553	616
Primary sclerosing cholangitis	748	425	1,173
Haemochromatosis	70,999	71,421	142,420
Total	4,029,600	4,062,739	8,092,339

3 Classification of costs

There are three types of costs associated with liver disease.

- **Direct health system costs** to the Australian health system include the hospital admitted patient services cost, out-of-hospital medical cost, prescription pharmaceuticals, funding for liver disease-related research, and national policy initiatives such as the national immunisation program.
- **Other financial costs** include patient productivity losses (i.e. absenteeism and employment impacts), premature mortality and the value of informal care. This also includes government and non-government programs such as respite, palliative care and funeral costs. Transfer costs comprise the deadweight losses associated with government transfers such as taxation revenue forgone and welfare payments are also categorised under other financial costs.
- **Non-financial costs** are also very important—the pain, suffering and premature death that result from liver disease. Although more difficult to measure, these can be analysed in terms of the years of healthy life lost, both quantitatively and qualitatively, known as the “burden of disease”.

Different costs of diseases are borne by different individuals or sectors of society. Clearly the patient bears costs, but so do employers, government, friends and family, co-workers, charities, community groups and other members of society.

It is important to understand how the costs are shared in order to make informed decisions regarding interventions. While the patient will usually be the most severely affected party, other family members and society (more broadly) also face costs as a result of liver disease. From the employer’s perspective, depending on the impact of liver disease, work loss or absenteeism will lead to costs such as higher wages (i.e. accessing skilled replacement short-term labour) or alternatively lost production, idle assets and other non-wage costs. Employers might also face costs such as rehiring, retraining and workers’ compensation.

While it may be convenient to think of these costs as being purely borne by the employer, in reality they may eventually be passed on to end consumers in the form of higher prices for goods and services. Similarly, for the costs associated with the health system and community services provided to the patient, although the Government meets this cost, taxpayers (society) are the ultimate source of funds. However, for the purpose of this analysis, a ‘who writes the cheque’ approach is adopted, falling short of delving into second round or longer term dynamic impacts.

Society bears both the resource cost of providing services to patients, and also the ‘deadweight’ losses (or reduced economic efficiency) associated with the need to raise additional taxation to fund the provision of services and income support.

Typically six groups who bear costs and pay or receive transfer payments are identified, namely the:

- patient;
 - friends and family (including informal carers);
- } The Household (i.e. at the individual level)

- employers;
- Federal government;
- State and local government; and
- the rest of society (such as non-government, not-for-profit organisations and workers' compensation groups).

Classifying costs by cost categories (health, other financial, disease burden) and allocating them to three groups (government, the individual/household and the 'rest of society' including employers) enables a framework for analysis of these data to isolate the impacts on the various groups affected by liver disease.

4 Health system costs

This chapter estimates the Australian health system expenditure due to liver disease. Health system expenditure includes hospital admitted patient services, out-of-hospital medical services, prescription pharmaceuticals, funding for liver disease-related research, and the cost of a national immunisation program.

4.1 Methods

There are essentially two ways of estimating health cost elements. They are:

- **Top-down:** Data may be able to provide the total costs of a program element and then allocate those costs by disease. The AIHW estimates health system expenditure by disease or disease groups such as liver disease.
- **Bottom-up:** Data may be available for the number of people with a disease who experience a cost impact from the disease ('n') and the average cost impact. The product is the total cost. For example, the number of people with liver disease multiplied by the average cost of a specialist visit.

For the purpose of this report, a top-down approach to costing is adopted.

4.2 International Classification of Diseases (ICD)

The ICD coding system is the standard diagnostic tool for epidemiology, health management and clinical purposes. This includes the analysis of the general health situation of population groups. It is used to monitor the incidence and prevalence of diseases and other health problems. It is also used to classify diseases and other health problems recorded on many types of health and vital records including death certificates and health records. In addition to enabling the storage and retrieval of diagnostic information for clinical, epidemiological and quality purposes, these records also provide the basis for the compilation of national mortality and morbidity statistics.¹³

The following table lists the ICD codes that are applicable to this analysis upon consultation with the clinical experts who formed the expert panel for this project. Special data requests such as those from the AIHW are based on this set of codes.

Table 4.1: ICD 10 codes (10th revision) for liver disease

Code	Description
K70-77	Diseases of the liver
C22	Intrahepatic cancers
B15-19	Viral hepatitis

¹³ For more details, refer to <http://www.who.int/classifications/icd/en/>.

Code	Description
I82	Budd-chiari
I85, I98.2, I98.3	Oesophageal varices
I86.4	Gastric varices
E83.0	Wilson's, Menkes
E83.1	Hemochromatosis, aceruloplasminemia

Source: WHO (2010) and advice from Expert Panel.

4.3 Hospital statistics

The hospital statistics were obtained from the AIHW's National Hospital Morbidity Database (NHMD). The data found in this database has been compiled from data supplied by the state and territory health authorities. It is a collection of electronic, confidentialised summary records for separations (that is, episodes of care) in public and private hospitals in Australia. Data are held for the years 1993-94 to 2009-10. Almost all hospitals in Australia are included in the database, i.e. public acute and public psychiatric hospitals, private acute and psychiatric hospitals, and private free standing day hospital facilities. The total number of records for 2009-10 was 8.5 million.

For the purpose of this study, the statistics obtained are based on the principal diagnosis which is defined as the diagnosis chiefly responsible for the patient's episode of care in hospital. The principal diagnosis is based on the ICD 10 codes as listed in Table 4.1.

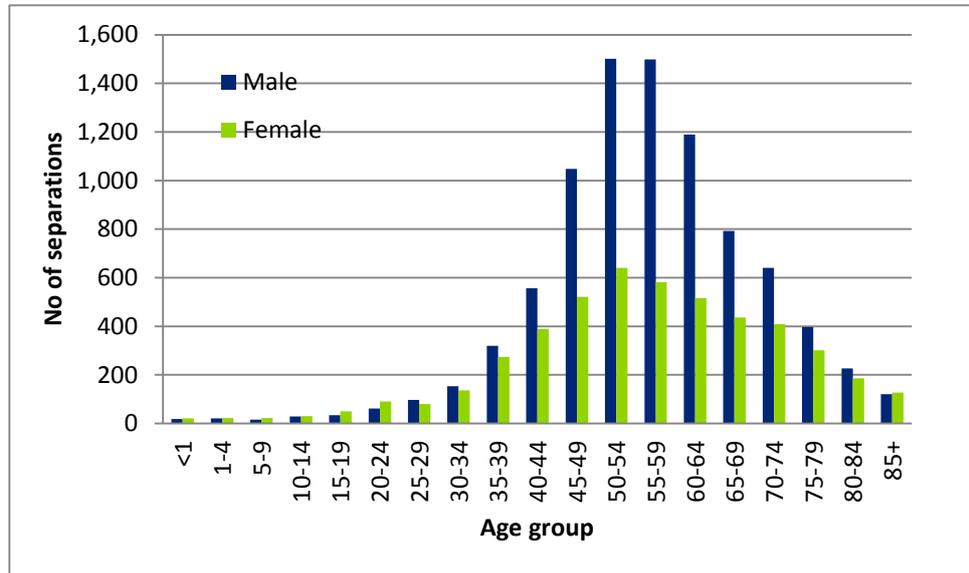
4.3.1 Diseases of the liver (K70-77)

In 2009-10, the total number of hospital separations for diseases of the liver was 13,555, male patients constituted 64%. Chart 4.1 presents the data by gender and age groups. As illustrated, most of the hospital separations were concentrated in the middle age groups, i.e. between 35 and 79 years of age.

As expected, similar patterns are observed for number of patient days by gender and age groups (see Chart 4.2). The total number of patient days was 86,863 with a mean of 2,286 per five year age group and a median of 1,674 during the same period.

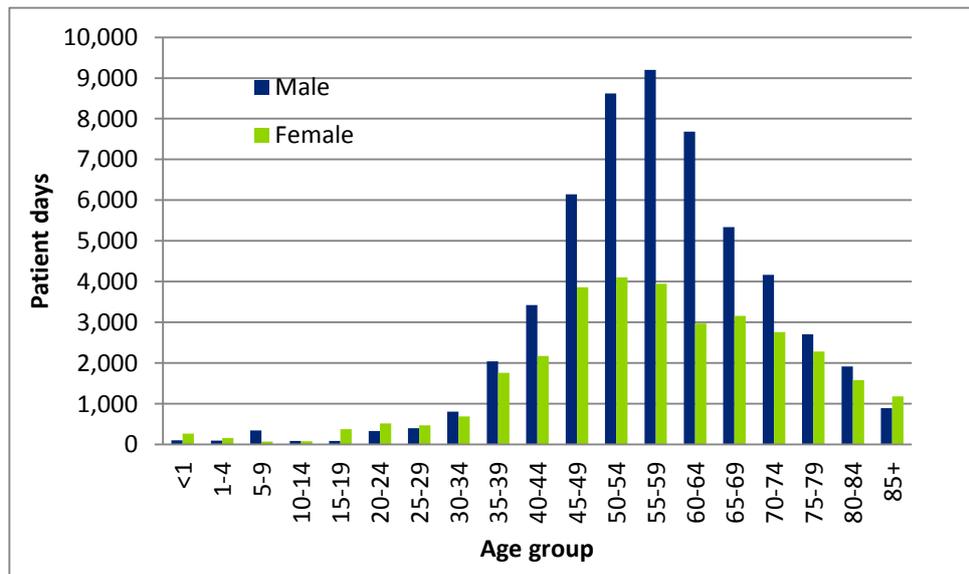
On average, the length of stay was 6.4 days for patients with a principal diagnosis of disease of the liver, i.e. K70-77.

Chart 4.1: Number of hospital separations by age and gender, K70-77, 2009-10



Source: AIHW (2011a).

Chart 4.2: Number of hospital patient days by age and gender, K70-77, 2009-10



Source: AIHW (2011a).

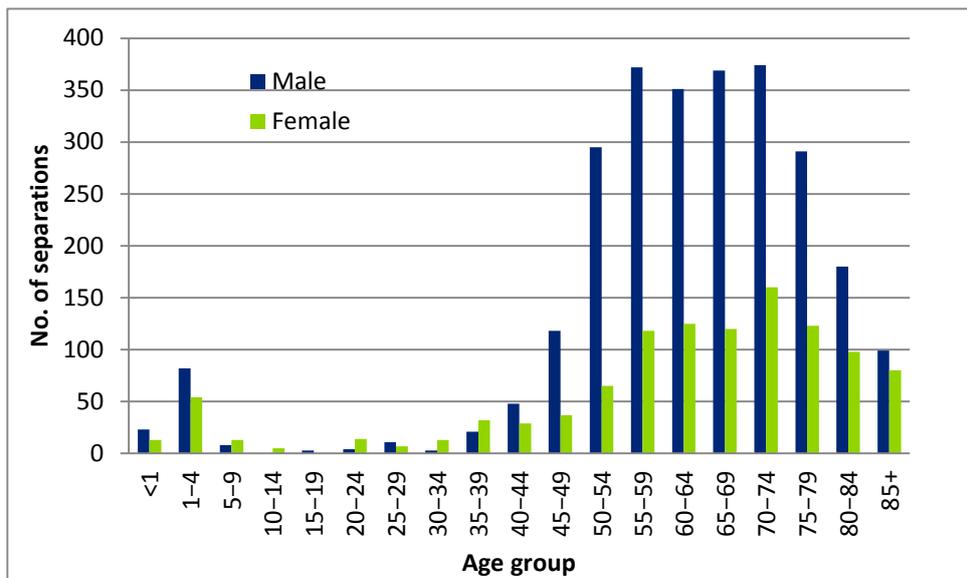
4.3.2 Primary liver cancer (C22)

For primary liver cancer, i.e. ICD 10 code C22, the total number of hospital separations in 2009-10 was 3,758, with a mean per five year age group of 658 and a median of 271. Similar to the diseases of the liver (section 4.3.1), the number of hospital separations was dominated by male patients, 68% versus 32% for female patients. Compared to the diseases of the liver in the previous section, most separations were concentrated in the much older age groups, i.e. aged 45 and above.

Similar patterns are observed for the number of patient days. The total number of patient days was 23,687, with a mean per five year age group of 104 and a median of 60. On average, the length of stay was 6.3 days.

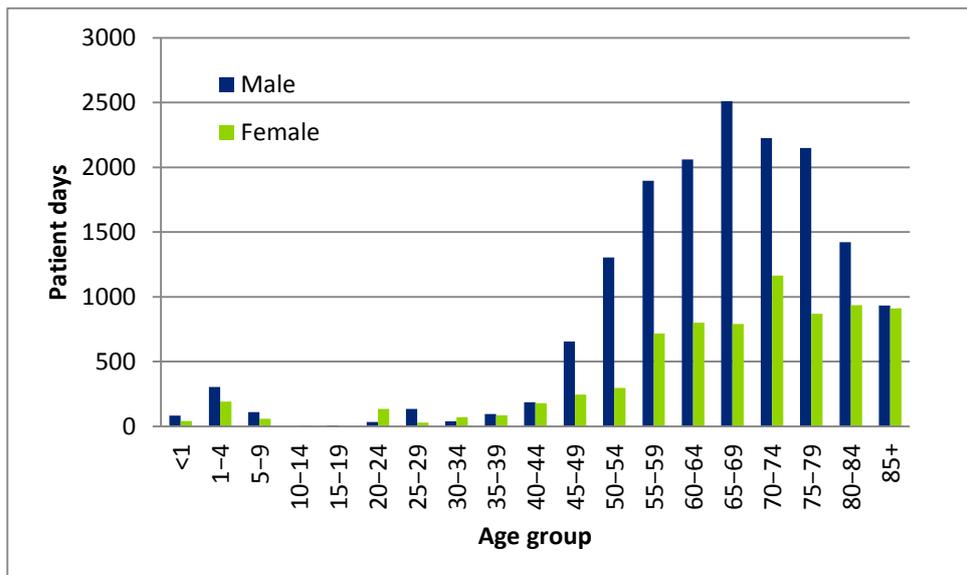
Chart 4.3 and Chart 4.4 illustrate the number of hospital separations and patient days respectively for primary liver cancer in Australia.

Chart 4.3: Number of hospital separations by age and gender, C22, 2009-10



Source: AIHW (2011a).

Chart 4.4: Number of hospital patient days by age and gender, C22, 2009-10



Source: AIHW (2011a).

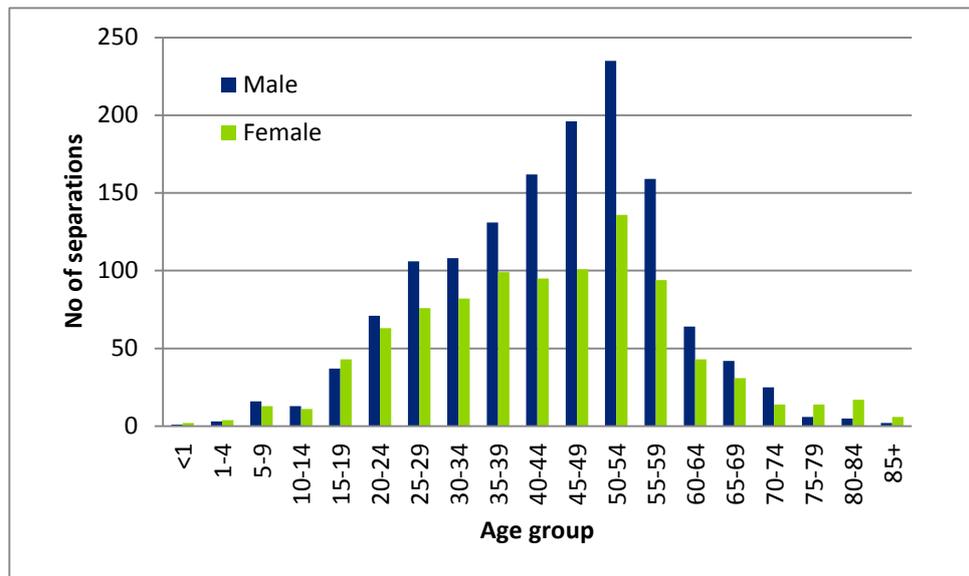
4.3.3 Viral hepatitis (B15-19)

For viral hepatitis, the total number of hospital separations in 2009-10 was 2,326, with a mean of 61 and a median of 43. Out of this total, male patients made up of 59% while female patients made up the remaining 41%. Compared with the patients with diseases of the liver and/or primary liver cancer, the patients diagnosed with viral hepatitis were much younger.

The total number of patient days was 6,379, with a mean per five year age group of 168 days and a median of 134. On average, the length of stay was 2.7 days.

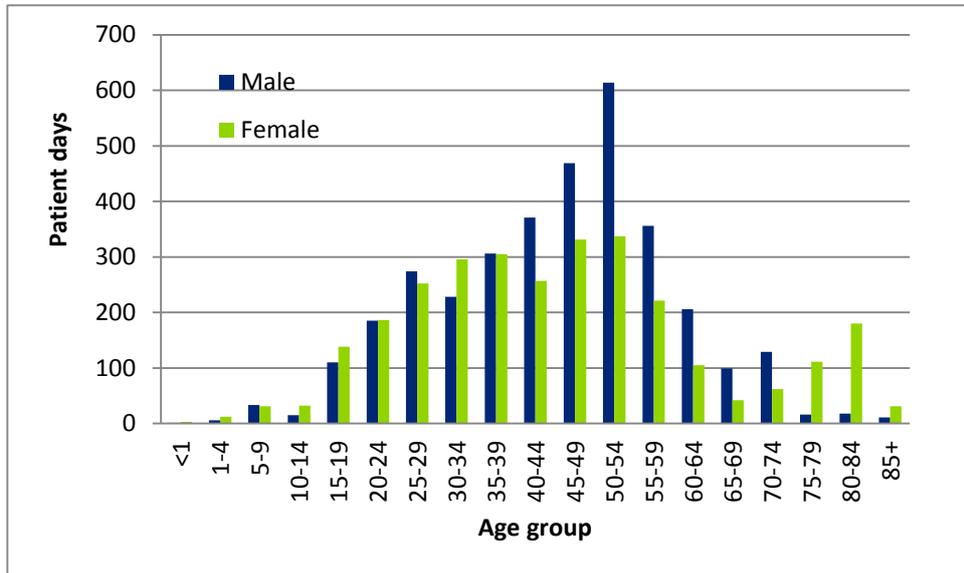
Chart 4.5 and Chart 4.6 illustrate the number of hospital separations and patient days respectively.

Chart 4.5: Number of hospital separations by age and gender, B15-19, 2009-10



Source: AIHW (2011a).

Chart 4.6: Number of hospital patient days by age and gender, B15-19, 2009-10



Source: AIHW (2011a).

4.3.4 All other liver disease (I82, I85, I86.4, I98.2, I98.3, E83.0 and E83.1)

The following table presents the hospital statistics for the rest of the liver disease categories, i.e. I82, I85, I86.4, E83.0 and E83.1.

Table 4.2: Hospital statistics for all other liver disease*, 2009-10

Disease type [^]	No. of separations	Average length of stay (days)	No. of patient days
<u>E83.0:</u>			
Male	12	7	79
Female	16	3	44
<u>E83.1:</u>			
Male	5,907	1	6,080
Female	2,652	1	2,804
<u>I82:</u>			
Male	365	5	1,868
Female	378	4	1,652
<u>I85:</u>			
Male	1,030	2	1,973
Female	505	2	1,029
<u>I86.4:</u>			
Male	154	4	558
Female	95	3	306

Note: *The hospital statistics for these disease categories are presented by gender only due to many missing cells when it is further segregated by age groups. [^]Only I98 data in total is currently available. Because of small

sample, AIHW did not split the data further to its sub-categories with I98. Consequently, I98.2 and I98.3 are excluded from the above table.

Source: AIHW (2011a).

4.4 Health expenditure

Health expenditure has been sourced from the AIHW disease expenditure database through a special data request using ICD 10 codes as listed in Table 4.1. Information on how health expenditure in Australia is distributed among disease and injury groups, by age and gender, is contained in this disease expenditure database. The latest data available is for 2008-09.

There are three main categories of expenditure that are relevant to this study (AIHW, 2012). They are:

- hospital admitted patient services – this includes public and private acute hospitals, and psychiatry hospitals;
- out-of-hospital medical services – this includes unreferral attendances, imaging, pathology, specialist attendances, and other services (if any); and
- prescription pharmaceuticals – this covers all pharmaceuticals for which a prescription is needed, including private prescriptions and below co-payment prescriptions, but excludes over the counter medicaments.

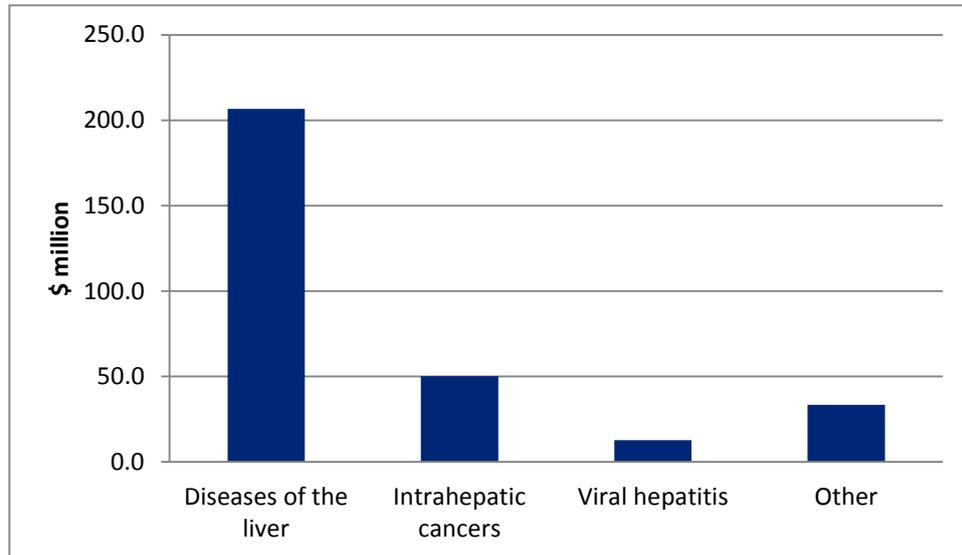
In order to reduce the number of non-reportable data, it was requested that the data for the three broad expenditure categories are broken down by the four main disease groups (i.e. K70-77, C22, B15-19, and the remaining ICD 10 codes as listed in Table 4.1). Separately, the age/gender distribution for the expenditure categories was obtained based on the sum of all the ICD 10 codes.

Further, because the expenditure data available from AIHW was for the year 2008-09, it was adjusted according to price changes and population growth during the period between 2008 and 2012 to bring the cost estimates up to date. Specifically, it was inflated using the average health inflation rate, i.e. approximately 4.5% per annum, based on ABS CPI data for health category (ABS, 2012a) and the average per annum Australian population growth rate of 1.5% for the period between 2008 and 2012 (ABS 2012e). Using this adjustment approach, **the total AIHW health expenditure associating with liver disease was estimated to be approximately \$386.2 million in 2012.**

The following charts, Chart 4.7, Chart 4.8 and Chart 4.9, depict the health system expenditure for each of the disease categories.

Chart 4.7 shows the total estimated cost for hospital admitted patient services for the year 2012. As expected, out of a total of \$303.0 million, patients with diseases of the liver constitute a high proportion of the total admitted patient cost, approximately 68% or \$206.6 million. This observation is consistent with the high number of patient days attributed to these individuals as described in section 4.3.1. The remaining \$96.4 million was spent on patients with primary liver cancer (\$50.2 million), viral hepatitis (\$12.8 million) and other liver diseases (\$33.5 million) respectively.

Chart 4.7: Estimated cost for hospital admitted patient services



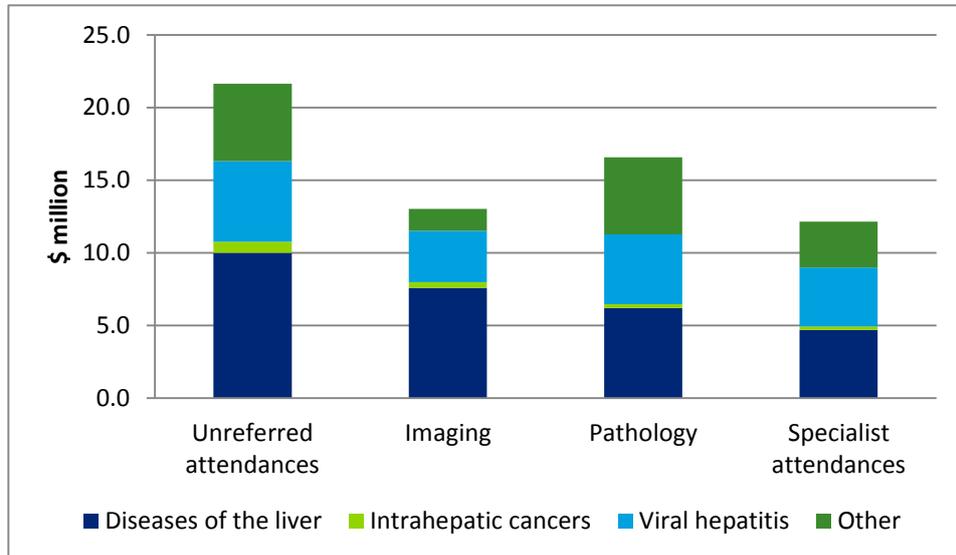
Note: (a) The estimated cost includes public and private acute hospitals, and psychiatric hospitals. It also includes medical services provided to private admitted patients in hospitals. (b)(i) Diseases of the liver refer to ICD 10 codes: K70-77; (ii) Intrahepatic cancers refer to ICD 10 code: C22; (iii) Viral hepatitis includes ICD 10 codes: B15-19; and (iv) Other refers to all other ICD 10 codes as listed in Table 4.1.

Source: ABS (2012a) and AIHW (2012).

Chart 4.8 presents the total estimated cost for out-of-hospital medical services by sub-categories – unreferral attendances, imaging, pathology and specialist attendances. In 2012, a total of \$63.2 million was spent providing out-of-hospital medical services. Unreferral attendances made up the highest proportion of the cost of out-of-hospital medical services at 34%, followed by pathology services at 26%, imaging at 21% and specialist attendances at 19%.

As previously observed, patients with diseases of the liver were the primary contributor for out-of-hospital costs. This observation holds true for all sub-categories of out-of-hospital medical services.

Chart 4.8: Estimated cost for out-of-hospital medical services

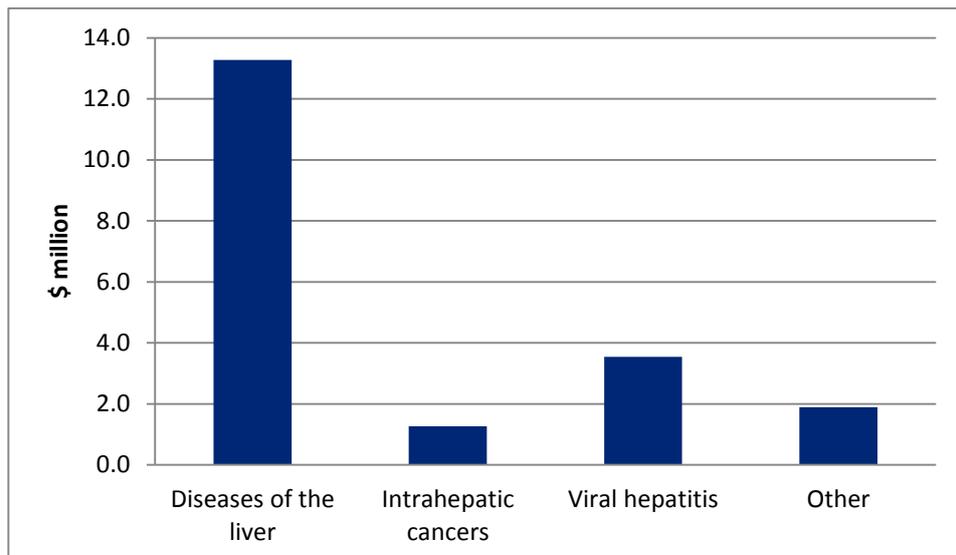


Note: (a)(i) Diseases of the liver refer to ICD 10 codes: K70-77; (ii) Intrahepatic cancers refer to ICD 10 code: C22; (iii) Viral hepatitis includes ICD 10 codes: B15-19; and (iv) Other refers to all other ICD 10 codes as listed in Table 4.1.

Source: ABS (2012a) and AIHW (2012).

The estimated cost for prescription pharmaceuticals is depicted in Chart 4.9 below. In 2012, the total estimated cost was approximately \$19.9 million with diseases of the liver sufferers constituting 67% of the total cost, followed by individual with viral hepatitis, i.e. 18%.

Chart 4.9: Estimated cost for prescription pharmaceuticals



Note: (a) The estimated cost includes all pharmaceuticals for which a prescription is needed, including benefit-paid prescriptions, private prescriptions and under co-payment prescriptions. (b) The estimated cost excludes over-the-counter medicaments such as vitamins and minerals, patent medicines, first aid and wound care products, analgesics, feminine hygiene products, cold sore preparations, and a number of complementary health products that are sold in both pharmacies and other retail outlets. (c)(i) Diseases of the liver refer to ICD

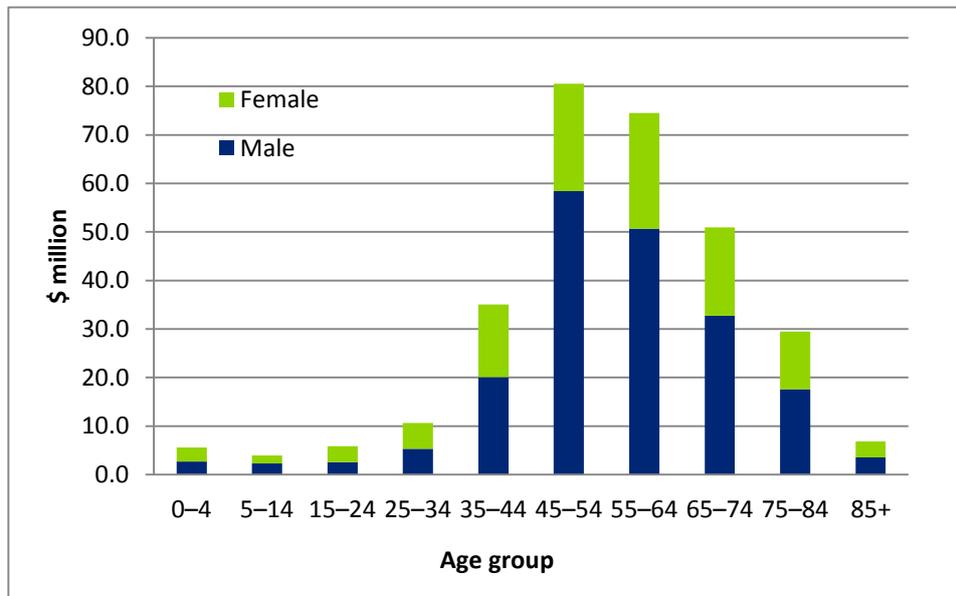
10 codes: K70-77; (ii) Intrahepatic cancers refer to ICD 10 code: C22; (iii) Viral hepatitis includes ICD 10 codes: B15-19; and (iv) Other refers to all other ICD 10 codes as listed in Table 4.1.

Source: ABS (2012a) and AIHW (2012).

As indicated earlier, the age/gender distribution for the expenditure categories was obtained based on the sum of all the ICD 10 codes.

The following charts (i.e. Chart 4.10, Chart 4.11 and Chart 4.12) present the each of the expenditure categories by age and gender. In general, male sufferers of liver diseases appear to incur higher costs relative to their female counterparts. Out of the total expenditure of \$386.2 million, two-third was incurred by male sufferers and the remaining by female sufferers. Estimated costs also tended to centre on individuals aged between 35 and 74 with the exception of prescription pharmaceuticals. Individuals aged between 75 and 84 incurred the most prescription costs relative to the other age groups.

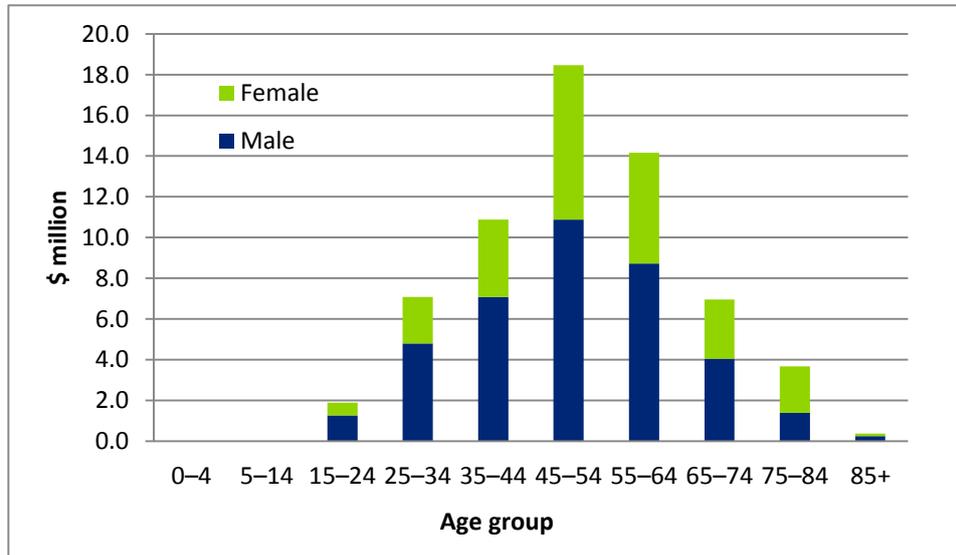
Chart 4.10: Estimated cost for hospital admitted patient services by age and gender



Note: (a) The estimated cost includes public and private acute hospitals, and psychiatric hospitals. It also includes medical services provided to private admitted patients in hospitals. c) Numbers may not add due to rounding.

Source: ABS (2012a) and AIHW (2012).

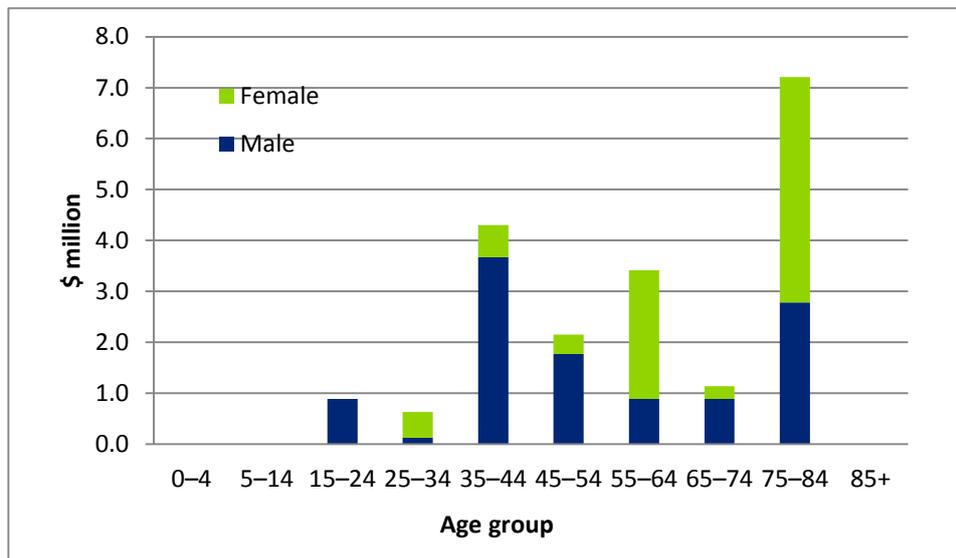
Chart 4.11: Estimated cost for out-of-hospital medical services by age and gender



(a) Numbers may not add due to rounding. (b) Some numbers such as those for aged 0-4 were either nil or rounded down to zero by AIHW.

Source: ABS (2012a) and AIHW (2012).

Chart 4.12: Estimated cost for prescription pharmaceuticals by age and gender



Note: (a) The estimated cost includes all pharmaceuticals for which a prescription is needed, including benefit-paid prescriptions, private prescriptions and under co-payment prescriptions. (b) The estimated cost excludes over-the-counter medicaments such as vitamins and minerals, patent medicines, first aid and wound care products, analgesics, feminine hygiene products, cold sore preparations, and a number of complementary health products that are sold in both pharmacies and other retail outlets. (c) Numbers may not add due to rounding. (d) Some numbers such as those for aged 0-4 were either nil or rounded down to zero by AIHW.

Source: ABS (2012a) and AIHW (2012).

In 2012, the total health expenditure associating with liver disease was estimated to be approximately \$386.2 million. Male sufferers of liver diseases made up two-third of the total costs and among these male sufferers, individuals aged between 35 and 74 contributed more than 50% of the total costs.

4.5 National immunisation program

The Immunise Australia Program is an Australian, State and Territory Government initiative which aims to increase national immunisation rates for vaccine preventable diseases. The Immunise Australia Program implements the National Immunisation Program Schedule which currently includes vaccines against a total of 16 diseases. Out of these 16 diseases, two are related to liver diseases; hepatitis A and hepatitis B.^{14, 15}

Hepatitis A vaccination is recommended as part of routine childhood immunisation for some Aboriginal and Torres Strait Islander children. The program is currently funding for all Aboriginal and Torres Strait children younger than five years of age living in Queensland, the Northern Territory, Western Australia and South Australia. Two doses of vaccine are given six months apart between 12 and 24 months of age. Immunisation against hepatitis A is achieved using a single-disease vaccine.¹⁶

Hepatitis B vaccination is currently funded for all children under the Immunise Australia Program. The first dose is given at birth, followed by another three doses at two, four and six or 12 months of age. Immunisation against hepatitis B is achieved using either single-disease or combination vaccines.¹⁷

Table 4.3 summarises the types of single-disease vaccine used and the circumstances under which the vaccine may be provided (Australian Government ComLaw, 2011).

¹⁴ <http://www.health.gov.au/internet/immunise/publishing.nsf/Content/diseases-a-z>

¹⁵ The full list of diseases are: Diphtheria, Haemophilus influenzae type B (Hib), Hepatitis A, Hepatitis B, Human Papillomavirus (HPV), Influenza (Flu), Measles, Meningococcal Disease, Mumps, Pertussis (Whooping Cough), Pneumococcal Disease, Poliomyelitis (Polio), Rotavirus, Rubella (German Measles), Tetanus (Lockjaw), and Varicella (Chickenpox).

¹⁶ <http://www.health.gov.au/internet/immunise/publishing.nsf/Content/immunise-hepa>

¹⁷ <http://www.health.gov.au/internet/immunise/publishing.nsf/Content/immunise-hepb>

Table 4.3: Viral Vaccines for hepatitis A and B

Vaccine and the circumstances in which vaccine may be provided	Brand and formulation	Active ingredient and strength	Number and timing of doses
<p><u>Vaccine:</u> Hepatitis A (monovalent)</p> <p><u>Circumstances:</u> Vaccine may be provided to a child:</p> <p>(a) who is an Aboriginal or a Torres Strait Islander; and</p> <p>(b) who is at least 1 year but less than 5 years; and</p> <p>(c) who lives in Queensland, Western Australia, South Australia or the Northern Territory</p>	VAQTA Paediatric/ Adolescent; Injection (0.5 ml)	Hepatitis A virus protein — 25 units of the hepatitis A virus protein	Two doses, with the second dose given six months after the first dose
<p><u>Vaccine:</u> Hepatitis B (monovalent adult)</p> <p><u>Circumstances:</u> Vaccine may be provided to a child who is at least 10 years but less than 14 years</p>	H-B-Vax II; Vial for injection (1mL)	Hepatitis B surface antigen protein — 10 µg	2 doses, with the second dose given 4 to 6 months after the first dose
<p><u>Vaccine:</u> Hepatitis B (monovalent paediatric)</p> <p><u>Circumstances:</u> Vaccine may be provided in the following circumstances:</p> <p>(a) a dose of the vaccine may be provided to a newborn infant as soon as practicable after birth but no later than 7 days after birth;</p> <p>(b) a first dose of the vaccine may be provided to a child who is at least 10 years but less than 14 years;</p> <p>(c) a second dose of the vaccine may be provided to a child mentioned in paragraph (b) 1 month after the first dose was provided to the child under paragraph (b);</p> <p>(d) a third dose of the vaccine may be provided to a child mentioned in paragraph (b) 5 months after the second dose was provided to the child under paragraph (c).</p>	Engerix-B; Vial for injection (0.5mL)	Hepatitis B surface antigen protein — 10 µg	1 dose or 3 doses
<p><u>Vaccine:</u> Hepatitis B (monovalent paediatric)</p> <p><u>Circumstances:</u> Vaccine may be provided to a newborn infant as soon as practicable after birth but no later than 7 days after birth</p>	H-B-Vax II; Vial for injection (0.5mL)	Hepatitis B surface antigen protein — 5 µg	1 dose

Note: The above table includes single disease vaccine only. There are other combination vaccines available for Hepatitis B immunisation but are not included in the table above.

Source: Australian Government ComLaw (2011). <http://www.comlaw.gov.au/Details/F2011L01025>

While the cost of vaccination for children is covered under the Immunise Australia Program, i.e. minimal out of pocket expenditure is envisaged, it still represents a cost to the health system. Table 4.4 provides an indicative price list of vaccines for hepatitis A and B.

Table 4.4: Price list of hepatitis A and B vaccinations

Vaccine	2011 price	2012 price
VAQTA hepatitis A vaccine	Adult: \$82.50 per injection; and Children: \$50 per injection.	Adult: \$85.50 per injection; Children: \$51.82 per injection.
HB Vax II * Energix Hepatitis B vaccine	\$30 per injection	\$31.09 per injection.

Note: The 2011 price is inflated using ABS Consumer Price Index (CPI) data for health category, i.e. 3.6% between 2011 and 2012 (ABS, 2012a).

Source: www.vaccinations.com.au

To estimate the cost of the immunisation program to the health system, it is assumed that for the year 2012, every new born child in Australia is vaccinated once and paid the full price under the Immunise Australia program. Moreover, the rate of vaccination for hepatitis B was 91.9% for children aged between 12 to less than 15 months in Australia (Department of Human Services, 2012)¹⁸. Therefore, for the purpose of the calculation of the cost of immunisation program, this vaccination rate is assumed to apply for both hepatitis A and hepatitis B vaccinations.

According to ABS (2012e), the number of births for Queensland, South Australia, Western Australia and the Northern Territory is estimated to be 61,860, 20,132, 32,318 and 4,343 respectively between June 2011 and March 2012.¹⁹ With the proportion of Aboriginal and Torres Strait Islander people relative to the total Australian population currently at 2.5% (ABS, 2012f), the number of Aboriginal and Torres Strait Islander births is then estimated to be 1,547, 503, 808 and 109 for Queensland, South Australia, Western Australia and the Northern Territory respectively. Assuming two doses of hepatitis A vaccination was consumed for each new born child and applying the rate of vaccination of 91.9%, **the cost of hepatitis A vaccination is estimated as \$282,531 in 2012.**

Similarly, the cost of hepatitis B vaccination was estimated by multiplying the total number of births in Australia (i.e. 295,409 between June 2011 and March 2012, annualised) by the cost of vaccination (i.e. \$31.09), the rate of vaccination (i.e. 91.9%) and the number of doses required (i.e. 4 doses). **In 2012, the cost of hepatitis B vaccination is thus estimated to be \$33.76 million.**

In 2012, the total cost of vaccinations for hepatitis A and hepatitis B was estimated to be around \$34.0 million.

¹⁸ Note the vaccination rate for children aged 24 months to less than 27 months is 94.5% in Australia. Given that that we have estimated the cost of vaccinations based on the number of new births, it is reasonable to use the vaccination rate based on younger cohort.

¹⁹ At the time of writing this report, only the March data was available for the year 2012. Consequently, the data for the previous three quarters (i.e. June 2011, September 2011 and December 2011) was used to estimate cost of vaccination instead.

4.6 Research funding

The National Health and Medical Research Council (NHMRC) administers funding for health and medical research on behalf of the Australian Government. Funding is available for all areas of research relating to human health and medicine. Once granted, the funding and its related information such as research areas and amount of funding are then recorded in the research funding statistics and database. According to this database, between 2000 and 2010, the total NHMRC funded research into liver disease amounted to more than \$121.8 million. This translates to an average of \$11.1 million per annum over the past 11 years. While these grants were awarded prior to 2012, there remain forward commitments for those grants which lasted a number of years. The table below provides an indicative estimate of the forward commitments after 2010. **For 2012, the total NHMRC forward commitments are estimated to be \$11.7 million.** Note that the total for all liver disease may not correspond to the summation of all individual categories. This is because some grants may involve more than one liver disease issue.

Table 4.5: NHMRC liver disease related grants (a) - forward commitments (b)

	2011	2012	2013	2014
Cirrhosis	\$3,480,907	\$3,202,958	\$1,745,570	\$1,604,000
Cholestasis	\$114,128	\$114,128	\$114,128	
Fatty Liver	\$584,721	\$376,004		
Haemochromatosis	\$1,968,682	\$865,026	\$210,725	
Menke's disease (c)	\$160,396	\$160,396		
Viral Hepatitis	\$7,588,869	\$7,588,869	\$4,896,320	\$413,128
Other	\$2,490,230	\$1,492,314	\$54,381	
All liver disease total	\$15,482,643	\$11,694,578	\$6,674,807	\$2,017,128

Note: (a) Some grants may involve more than one liver disease issue. Aggregating the data will therefore *not* equal the 'all liver disease' totals. (b) Forward commitments funding data for out-years is subject to change when new grants are awarded in subsequent years; the estimate is for the spend in that year. (c) Menke's disease is a genetic condition but is included by the NHMRC and is retained for completeness, since only the total is used in the estimates and this would not change if Menke's disease were excluded, as per note (a).

Source: NHMRC (2011)

Based on the forward commitments indicated by the NHMRC funding database, around \$11.7 million would be spent on research related to liver disease in 2012.

4.7 Summary of health system costs

The total health system costs associated with liver disease are estimated to be \$432 million.

Table 4.6: Summary of health system costs

Health system costs	2012 (\$ million)
Health expenditure	386.2
National immunisation program	34.0

Research funding	11.7
Total	432.0

As indicated earlier, allocating expenditure to different payer groups (such as government, the individual/household, and the 'rest of society' including employers) enables a framework upon which the impacts on the various groups affected by liver disease can be analysed. The AIHW (2012a) reported that the total health expenditure paid by the Australian government is 42.7% of the total expenditure. State, territory and local governments contribute 26.4%, and individuals, family and friends 18.3%. This means the health system costs related to liver disease are largely borne by the Australian government (\$184.4 million) and state, territory and local governments (\$114.0 million). Individuals, family and friends contribute \$79.0 million, while the rest of the society (e.g. private health insurers, compensation) makes up the remaining \$54.4 million.

Table 4.7: Summary of health system cost by payer groups

Health system costs	2012 (\$ million)	Proportion (%)
Federal government	184.4	42.7%
State/territory	114.0	26.4%
Individuals, family and friends	79.0	18.3%
Other parties	54.4	12.6%
Total	432.0	100%

5 Other financial costs

Other financial costs are all those that are not ‘direct’ health system costs (Section 4) nor intangible costs – the loss of health and wellbeing (Section 6). It is also important to make the economic distinction between real and transfer costs to avoid double counting.

- **Real costs** use up real resources, such as capital and/or labour, or reduce the economy’s overall capacity to produce goods and services.
- **Transfer payments** involve payments from one economic agent to another that do not use up real resources, for example, taxation revenue or carer allowance and payment.
 - Transfer costs are important when adopting a whole-of-economy analysis of the impact of a particular disease.

5.1 Productivity losses

Liver disease can affect individuals’ capacity to work. They may work less than they otherwise would, retire early, be absent from work more often, or die prematurely. If employment rates are lower for people with liver disease, this loss in productivity represents a real cost to the economy. Additionally, informal carers may also work less or not work entirely in order to care for their loved one with liver disease, and this represents an additional productivity loss.

Deloitte Access Economics measures the lost earnings and production due to health conditions using a ‘human capital’ approach. The lower end of such estimates includes only the ‘friction’ period until the worker can be replaced, which would be highly dependent on labour market conditions and unemployment/underemployment levels. In an economy operating at near full capacity, a better estimate includes costs of temporary work absences plus the discounted stream of lifetime earning lost due to early retirement from the workforce, reduced working hours (part-time rather than full time) and premature mortality, if any.

In this case, it is likely that, in the absence of disease, people with liver disease in each age-gender group would participate in the labour force and obtain employment at the same rate as the general population in Australia, and earn the same average weekly earnings. The implicit and probable economic assumption is that the numbers of such people would not be of sufficient magnitude to substantially influence the overall clearing of the labour market.

5.1.1 Employment rates

Survey of Disability, Ageing and Carers (SDAC)

The 2009 SDAC survey is a national survey conducted by the ABS throughout Australia, from April to December. The primary objective of the survey is to collect detailed information about three population groups. They are:

- people with a disability;

- older people (i.e. those aged 60 years and over); and
- people who provide assistance to older people and people with disabilities.

Information was also collected on people who were not in these populations, allowing for comparison of their relative demographic and socioeconomic situations. In addition to people living in private dwellings, those in cared accommodation, such as nursing homes, were also surveyed. Data on long-term health conditions was based on self-identification rather than clinical diagnosis, and time elapsed since diagnosis was not reported. The survey uses questions about activity limitation to screen respondents before asking questions about conditions present, and thus may miss people with liver disease without activity limitation – for example those in the very early stages of diagnosis, and those who have finished their treatment regimes. Consequently the SDAC estimate of prevalence is more likely to identify people currently undergoing treatment.

Another limitation in relation to SDAC data is the inability to specifically identify liver disease using the three-digit ICD 10 codes as presented in Table 4.1. The data is instead reported by broad disease categories. For instance, the category *diseases of the digestive system* includes liver disease alongside a myriad of other conditions; *neoplasms* would cover liver cancer plus other carcinomas; and *infectious and parasitic diseases* would include viral hepatitis. Consequently, it is necessary to proxy the employment rate for liver disease using these higher level health conditions. Further, to improve precision because of the small survey sample size²⁰, the average employment rates for these three high level conditions by gender are presented in the Table 5.1. As indicated, relative to the general population, the employment rates for individuals with any of the three health conditions are much lower, i.e. 5.8% and 15.0% lower for males and females respectively.

Table 5.1: Average employment rates (%) across three high level health categories*, SDAC

Aged 15-64	Patients	General population	Difference
Male	69.5%	75.3%	-5.8%
Female	49.4%	66.4%	-15.0%
Average	59.4%	69.9%	-10.4%

Note: *These three high level health categories are: (a) other neoplasms (tumours/cancers); (b) certain infectious and parasitic diseases; and (c) diseases of the digestive system.

Source: ABS (2010) and (2012).

International literature

A literature review revealed numerous international studies which have examined the impact of cancer on employment rates. For instance, Short et al (2005) reported that on average, the existence of cancer reduced the employment rate by 16%. Others such as Weis et al (1992) reported the impact to be as high as 59%. While there is a lack of literature that examines liver cancer in specific detail, it would be reasonable to use the weighted average of the existing international studies to estimate the impact of liver cancer on employment rates in Australia. Using this weighted average approach, the impact of cancer would reduce the employment rate by 27% (Table 5.2).

²⁰ The total sample sizes for all the three health conditions are: 155 for males and 132 for female.

Table 5.2: International studies on the impact of cancer on employment

Study	Cancer	No. of respondents	Years since diagnosis	Impact on employment*
Cross Sectional				
Bradley et al (2002)	Breast	39	<=2	-10%
Bradley et al (2005)	Breast	117	>=3	-6%
Longitudinal				
Satariano and DeLorenzo (1996)	Breast	296	1	-28%
Maunsell (2004)	Breast	646	3	-21%
Bushunow et al (1995)	Breast	145	6	-7%
Greenwald et al (1989)	Mixed	247	1	-50%
Stayley et al (1987)	Mixed	61	1	-10%
Short et al (2005)	Mixed	1372	4	-16%
Weis et al (1992)	Mixed	377	4	-59%
Main (2005)	Mixed	27	7	-19%
van der Wouden et al (1992)	Mixed	309	8	-56%
de Lima et al (1997)	Leukaemia	181	3	-26%
Razavi et al (1993)	Lymphoma	41	4	-46%
Weighted Average		3,858	3.7	-27%

Note: * In the cross sectional analysis this is the difference in employment rates between cancer survivors and the control group, controlling for other factors. While in the longitudinal analysis this is the proportion of cancer survivors who were employed at diagnosis, who are employed at a point in time after diagnosis.

Source: As indicated in the table.

Jacobs et al (2003) examined the employment rates of a sample of persons aged 18-65 years, with and without serological evidence of Hepatitis C virus infection, and with normal or elevated levels of alanine aminotransferase (ALT). After controlling for the potential confounding effects of demographic, social, and economic factors, a positive Hepatitis C status but normal ALT level in males was associated with a 10.7% reduction in labour force participation relative to the control group, i.e. those with negative Hepatitis C status. Positive Hepatitis C status and elevated ALT level was associated with a 17.5% reduction in employment. On average, the results translated to a 14.1% reduction in employment rate due to Hepatitis C. The results for females were not statistically significant.

While the international literature may not be directly comparable with the Australian context, it does provide a baseline to ensure the results from the SDAC survey are sensible. Given that the average employment rates sit at the lower end of the cancer and hepatitis literature, for the purpose of estimating the productivity losses, the SDAC results are used, based on age and gender group.

Given the lack of symptoms of both NAFLD and haemochromatosis (see sections 2.3 and 2.7), it is reasonable to assume that there would be limited productivity losses associated with them. However, severe cases of NAFLD could lead to liver failure. Not including those individuals with severe cases would lead to an underestimation of productivity losses. Consequently, the number of deaths associated with NAFLD, i.e. 2,264, is assumed to be NAFLD-related cirrhosis and is used to estimate the productivity losses associated with NAFLD. This is still potentially conservative.

Using the average weekly earnings (AWE) based on ABS (2012c) multiplied by the number of people that are not employed due to liver disease, this translates into approximately \$2.1 billion lost in productivity in 2012 alone.

In 2012, the productivity cost associated with lower employment rate was estimated as \$2.1 billion.

5.1.2 Absenteeism

Some people will remain in the workforce in the early stages of liver disease, either because they are not yet diagnosed or because they need or want to continue to work. Remaining in employment is more likely if the illness is in the early stages, if the work environment is supportive, if tasks are familiar or repetitive, and if supervision and occupational health and safety arrangements are adequate. These people may, however, be absent from work more often than those without liver disease as a result of the condition – because they need to take time off for medical appointments, to organise their affairs, or because of their symptoms. This absenteeism represents further productivity losses.

Two studies were identified that estimate average days absent from work of employed people with cancer – although not just liver cancer.

- A US study interviewed 445 employed people with breast or prostate cancer and found that 93% of people with breast cancer and 82% of people with prostate cancer missed at least one day of work over a period of six months from diagnosis, and on average they missed 44.5 days and 27 days from work, respectively (Bradley 2005).
- The National Health Survey estimated that, of employed people with stomach, liver and pancreas cancer, on average they lost 22.5 days from work over 12 months per employed person. While this estimate includes people with cancer taking time off for work due to non-cancer related reasons, this estimate may underestimate the days absent as the survey may capture cancer survivors rather than people actively being treated for cancer, thus lowering the average days absent (Access Economics 2005).

Another four studies were identified that estimated the impact of hepatitis C on absenteeism of employed people.

- Su et al (2010) found that in the US, employees with hepatitis C had significantly more lost work days per employee than the control cohort (i.e. without hepatitis C). They estimated that, on average, hepatitis C infected workers had 4.15 more days of absence per employee than the control cohort.
- Two other US studies DiBonaventura et al (2011) and Brooks et al (2011) also found that patients with hepatitis C reported significantly higher levels of absenteeism than the control group. DiBonaventura et al (2011) estimated that the level of absenteeism for persons with hepatitis C was 4.88% versus 3.03% for the control group while Brooks et al (2011) found that hepatitis C positive workers had 0.52 more total monthly absence days. This translated to around 6.24 days per year.
- Liu et al (2012) estimated the level of absenteeism due to hepatitis C infection in Japan. Consistently with the US studies, it was found that the hepatitis C infected group had

significantly higher workplace absenteeism than the control group (8.59% versus 4.12%).

The literature consistently found that persons with cancer or hepatitis C infection had higher level of absenteeism than their healthy counterparts leading to further productivity losses. To estimate this additional productivity loss, the number of absence days from the National Health Survey (i.e. 22.5 days) is used for individuals with liver cancer while the average number of absence days based on Su et al (2010) and Brooks et al (2011) (i.e. 5.2 days) was used to proxy for the number of absence days for individuals with hepatitis and other liver disease.

In 2012, the additional productivity losses due to a higher level of absenteeism are estimated to be \$1.2 million for individuals with liver cancers, and \$206.0 million for individuals with hepatitis and other liver disease. Therefore, the total cost of additional productivity losses is \$207.1 million.

5.1.3 Premature death

There are also production losses arising from premature mortality associated with liver disease. The income forgone for those who die prematurely would be estimated based on the assumption that if those who died had lived and not had liver disease, they would have been employed at the same rate as the general population. This would therefore represent future productivity loss, measured as the net present value (NPV) of future lost income streams for those people who die from liver disease prior to when they would otherwise have retired.

The NPV of premature mortality due to liver disease is then estimated using retirement age, average life expectancy, and average age of death. Additionally, premature death also leads to additional search and hiring costs for replacement workers. These are estimated by multiplying the number of people with liver disease who die prematurely by their chance of being employed multiplied by the searching and hiring cost brought forward three years – the searching and hiring cost is estimated as 26 weeks at average weekly earnings (AWE) and the three year bring forward reflects the average staff turnover rates in Australia.

As indicated in sections 2.2.2 and 2.6.1.4, chronic hepatitis B and PSC patients have higher a chance of developing primary liver cancer. It is therefore likely that many deaths associated with hepatitis B and PSC are cancer-related. So as to avoid double counting, the number of deaths related to PSC and hepatitis B are excluded. They are assumed to be included within the deaths associated with primary liver cancer, i.e. 1,270.

In 2012, the total production losses arising from premature mortality associated with liver disease are estimated to be approximately \$1.9 billion.

5.2 Carer costs

Carers are people who provide informal care to others in need of assistance or support. Most informal carers are family or friends of the person receiving care. Carers may take time off work to accompany people with liver diseases to medical appointments, stay with

them in hospital, or care for them at home. Carers may also take time off work to undertake many of the unpaid tasks that the person with liver disease would do if they did not have the disease and were able to do these tasks.

Informal care is distinguished from services provided by people employed in the health and community sectors (formal care) because the care is generally provided free of charge to the recipient and is not regulated by the government.

While informal care is provided free of charge, it is not free in an economic sense, as time spent caring is time that cannot be directed to other activities such as paid work, unpaid work (such as housework or yard work) or leisure. As such, informal care is a use of economic resources.

5.2.1 Methodology

There are three potential methodologies that can be used to place a dollar value on the informal care provided.

- **Opportunity cost** is the value of lost wages forgone by the carer.
- **Replacement valuation** is the cost of buying a similar amount of services from the formal care sector.
- **Self-valuation** is what carers themselves feel they should be paid.

The self-valuation method is not commonly used, as there is no reliable Australian studies of the amount Australian carers feel they should be compensated. Estimates of the value of informal care are very sensitive to the estimation methodology used. In this study, Deloitte Access Economics has adopted the opportunity cost method as it provides the most accurate estimate of carer costs based on AWE.

Note that some people with liver disease and their carers may actually increase their productivity (at the expense of their leisure time) in order to pay for their increased disease-related expenses or as a distraction from the illness. However, due to a lack of data, this effect was not captured in this analysis.

5.2.2 Primary carer cost estimation

The SDAC data provides the most recent and comprehensive profile of Australians with health conditions and disability, and the people who provide them with assistance and support. As highlighted earlier (see section 5.1.1), SDAC data only includes high level health conditions. Therefore, consistent with earlier approach, the aggregate number of carers and care hours for the three high level health conditions (i.e. other neoplasms (tumours/cancers)²¹, certain infectious and parasitic diseases, and diseases of the digestive system) were used.²²

²¹ This excludes breast and prostate cancers.

²² The total survey sample size relating to these three conditions is 36.

Table 5.3: Primary carers of people within the three high level health categories*, 2009

	No. of primary carers
<u>Male:</u>	
Aged 15-64	6,136
Aged 65+	1752
Total	7,888
<u>Female:</u>	
Aged 15-64	4,622
Aged 65+	1878
Total	6,501
<u>Persons</u>	
Aged 15-64	10,758
Aged 65+	3630
Total	14,388

Note: *These three high level health categories are: (a) other neoplasms (tumours/cancers); (b) certain infectious and parasitic diseases; and (c) diseases of the digestive system. These relate to the main disabling condition of the main recipient of care.

Source: ABS (2010).

Clearly, Table 5.3 includes the total number of carers across all three high level health categories. Consequently, the proportions of primary liver cancer, liver diseases and viral hepatitis within the high level conditions based on AIHW hospital separation statistics (see section 4.3) were applied. This translates into the number of carers for liver disease as presented in the table below. In total, in 2009, there were 590 primary carers of people with liver diseases, of which 74.8% were of working age.

Table 5.4: Primary carers of people liver disease, 2009

	No. of primary carers
<u>Male:</u>	
Aged 15-64	252
Aged 65+	72
Total	324
<u>Female:</u>	
Aged 15-64	190
Aged 65+	77
Total	267
<u>Persons</u>	
Aged 15-64	442
Aged 65+	149
Total	590

Source: ABS (2010) and AIHW (2011).

SDAC only reports hours of informal care provided per week for primary carers. As before, the total number of informal care hours was obtained for the three high level health categories and proportioned accordingly based on the AIHW hospital statistics.

Table 5.5: Total hours of informal care provided to people with liver disease

	<20 hours per week	20-39 hours per week	40+ hours per week	Not stated	Average hours per week
Male	27%	24%	49%	0%	34.2
Female	17%	15%	66%	2%	39.2
Person	23%	20%	57%	1%	36.5

Note: 10 hours, 29.5, and 50 hours per week was imputed in the <20 hours, 20-39 hours, and 40+ hours per week groups, respectively. Further, the lowest category, i.e. 10 hours per week was used to impute for those who did not state the number of hours per week.

Source: ABS (2010) and AIHW (2011).

The opportunity cost method for estimating the carer costs is calculated by multiplying the total number of informal hours of care by average employment rate and AWE and then dividing by the average hours worked. Based on this estimation approach, the cost of carers is estimated to be \$258.7 million in 2012.

Based on the opportunity cost estimation approach, the total carer costs in Australia for liver disease is \$258.7 million in 2012.

5.3 Program payments

5.3.1 National respite for carers program (NRCP)

The NRCP contributes to the support and maintenance of caring relationships between carers and their dependent family members or friends by providing access to information, respite care and other flexible respite support appropriate to individual carer need and the needs of the people for whom they care. According to AIHW (2009), the NRCP provides information and support to carers of frail older people and carers of people with disability through the following:

- Commonwealth Respite and Carelink Centres, which provide a single point of contact for members of the community, carers, health professionals and others needing information about community care and other support services in local areas to assist people to live independently.
- the provision of respite through community-based agencies which can be arranged by direct approach to the respite care provider, or can be coordinated by a Commonwealth Respite and Carelink Centre.
- the delivery of professional counselling through the National Carer Counselling Program, and carer advisory and information services through the Carer Information and Support Program.

Funding for NRCP was around \$200.0 million in 2009-10 and this has increased from \$139.4 million in 2005-06 (Steering Committee for the Review of Government Service

Provision (SCRGSP), 2007-2011). This represents an average increase of 10% per annum during the period. Table 5.6 presents the yearly funding for NRCP between 2005-06 and 2009-10 (SCRGSP, 2007-2011).

Table 5.6: NRCP funding, 2005-06 to 2009-10

Year	Funding (\$ million)	No. of people assisted	Funding per person assisted
2005-06	\$139.4	108,197	\$1,288
2006-07	\$166.9	129,803	\$1,286
2007-08	\$173.5	125,507	\$1,382
2008-09	\$193.3	127,504	\$1,516
2009-10	\$200.0	143,387	\$1,395
Average per year	\$174.6	126,880	\$1,373

Source: SCRGS (2007-2011).

Given the lack of data available, the NRCP funding for 2011-12 was projected based on the average per year funding as well as the average yearly number of people assisted as indicated in the above table. As a result, the NRCP funding for 2011-12 was estimated to be around \$209.9 million.

According to the Australian National Audit Office (ANAO) (2004-05) report, the group targeted by NRCP and the proportion of services provided to each group is presented in Table 5.7.

Table 5.7: Carers targeted under NRCP funding

Target group	% Target
Carers of people with dementia	28.1%
Carers of frail aged people (65 years or over, or 50 and over if Indigenous)	21.9%
Carers of people with dementia and challenging behaviours	21.6%
Carers of young people (under 65 or under 50 if Indigenous) with moderate, severe or profound disabilities	21.2%
Carers of people with a terminal illness in need of palliative care; who are living at home	5.5%
Unspecified*	1.7%

Note: It is possible that actual provision across target groups differs to funding objectives stated above.

Source: ANAO (2004-05).

Assuming the services were provided in line with funding objectives i.e. 5.5% of expenditure was on services for carers of people receiving palliative care and 89.8% of patients in community based palliative care programs have cancer as a principle diagnosis (Palliative Care Australia, 1998), then the total expenditure in 2012 on respite for carer of primary liver cancer patients is estimated to be \$0.3 million with a cost per death of \$259.70.

Note that given a high proportion of palliative care patients' diagnosis was cancer-related, the primary focus is thus placed on primary liver cancer. Therefore, the above approach would most likely produce an underestimate of the cost of respite services as other liver disease such as viral hepatitis was not included.

In 2012, the total expenditure on respite for carer of primary liver cancer patients is estimated to be \$0.3 million.

5.3.2 Palliative care

Palliative care is the specialised care provided for people who are dying from active, progressive and far-advanced diseases, with little or no prospect of cure. The aim of palliative care is to achieve the best possible quality of life, both for the person who is dying and for their family.

Services are provided by both government and non-government organisations, delivered by family and friends, general practitioners, and palliative care specialists, and provided in:

- inpatient units, hospices, residential and aged care facilities; and
- in the homes of patients (supported by community-based programs and consultancy services).

State and Territory governments have the primary responsibility for management of palliative care services in Australia, while the Federal government has an oversight role (responsible for planning and strategy).

Palliative care in Australia is funded from a range of sources, including the Federal government, State and Territory governments, health funds, private donations and fundraising. According to the Senate Community Affairs Committee (2012), the total federal funding palliative care has received over the period 2002-03 to 2011-12 inclusive totalled \$506.9 million in real terms (2011-12 dollars). This translates to a year average of around \$56.3 million over the nine year period.

Palliative care programs were broken down into five classifications (community, inpatient, consultative (hospital), outpatient clinic, day centre). For the 1998 census conducted by Palliative Care Australia, it was estimated that 11,902 patients were registered in palliative care programs, of which around 10,680 (90%) had cancer as a principle diagnosis.

Based on the total funding, the proportion of palliative care patients diagnosed with cancer and the number of cancer-related deaths, the cost per cancer death as well as the total cost for palliative care is estimated to be \$1.6 million in 2012, with a cost per cancer death at \$1,266.70.

As before, given a high proportion of palliative care patients' diagnosis was cancer-related, the primary focus is placed on primary liver cancer.

The total expenditure in 2012 on palliative care for primary liver cancer patients is estimated to be \$1.6 million.

5.4 Funeral costs

The 'additional' cost of funerals borne by family and friends of people with liver disease is based on the additional likelihood of deaths associated with liver disease (Section 6.3.3) in

the period that the person is diagnosed with the disease. However, some patients (particularly older patients) would have died during this time anyway. Eventually everyone must die and thus incur funeral expenses – so the true cost is the cost brought forward (adjusted for the likelihood of dying anyway in a given year). The Bureau of Transport Economics (2000) calculated a weighted average cost of a funeral across all states and territories, to estimate an Australian total average cost of \$3,200 per person in 1996, or, inflated using CPI, \$4,946 per person who died in 2012.

In Australia, the bring forward of funeral costs associated with premature death are estimated based on the cost of bringing forward the funeral multiplied by the number of premature deaths.²³ The bring forward of funeral costs is estimated to be \$33.9 million in 2012.

In 2012, the bring forward of funeral costs associated with premature death are estimated based on the cost of bringing forward the funeral multiplied by the number of premature deaths are estimated to be \$33.9 million.

5.5 Transfers

5.5.1 Welfare payments

There are a number of welfare payments that are currently available to individuals with illnesses, diseases and/or disability as well as their carers. The following are a list of payments that constitute significant income sources for patients and their carers.

- **Disability support pension:** available for people who have a permanent physical, intellectual or psychiatric impairment. It is designed to give people an adequate means of support if they are unable to work for at least 15 hours per week at or above the relevant minimum wage, independent of a program of support.
- **Newstart allowance:** available if not employed and *temporarily* unable to work because of a medical condition (which exempts the person from the Activity Test).
- **Sickness allowance:** available if employed (and can return to the job) or studying and *temporarily* unable to work/study because of a medical condition (as long as there is a job or study to return to after recovery).
- **Carers payment:** available for people who are unable to support themselves through participation in the workforce while caring for someone with a disability, severe medical condition or who is frail and aged.
- **Carers allowance:** available for carers who provide daily care and attention at home for a person with a disability, severe medical condition or who is frail and aged. Carer allowance may be paid in addition to income support payments.

Currently, the data for each welfare payment are related to a list of main conditions. The main conditions relevant for this study are cancer/tumour and infectious diseases for disability support payments, and Hepatitis A, B, C, D – H, liver cancer, and liver disorder (i.e. cirrhosis but not hepatitis) for the remaining welfare payments mentioned above.

²³ As before, all the deaths associated with Hepatitis B and PSC are conservatively excluded. They are assumed to be counted within liver cancer-related deaths.

Our understanding from the Department of Human Service (DHS) is that data provided to us for Newstart Allowance and Sickness Allowance payments were not made *due* to liver diseases; consequently, they were excluded. In addition, because further splits by disease conditions were not possible, the number of Disability Support Pension recipients due to liver diseases was not known (i.e. we could not separate liver cancer from other cancers for example). As a result, Disability Support Payments were also excluded in this analysis. The following table thus presents the total Carer Allowance and Carer Payment amounts as of 29 June 2012, by age group.

Table 5.8: Carer Payment and Carer Allowance by age group as of 29 June 2012

Age group	\$'million
16-24	\$0.46
25-34	\$1.67
35-44	\$5.48
45-54	\$15.13
55-64	\$17.33
65+	\$13.66
Total	\$53.74

Note: The fortnightly rates used are: Carer Allowance - \$114; and Carer Payment - \$712. The DHS data is as of 29 June 2012.

Source: Deloitte Access Economics estimation based on DHS special data request.

As of 29 June 2012, the total Carer Allowance and Carer Payment due to liver disease were estimated to be approximately \$53.74 million.

5.5.2 Deadweight losses (DWLs)

Transfer payments represent a shift of resources from one economic entity to another. The act of taxation and redistribution creates distortions and inefficiencies in the economy hence transfers also entail real net costs to the economy. These real net costs are termed 'DWLs'.

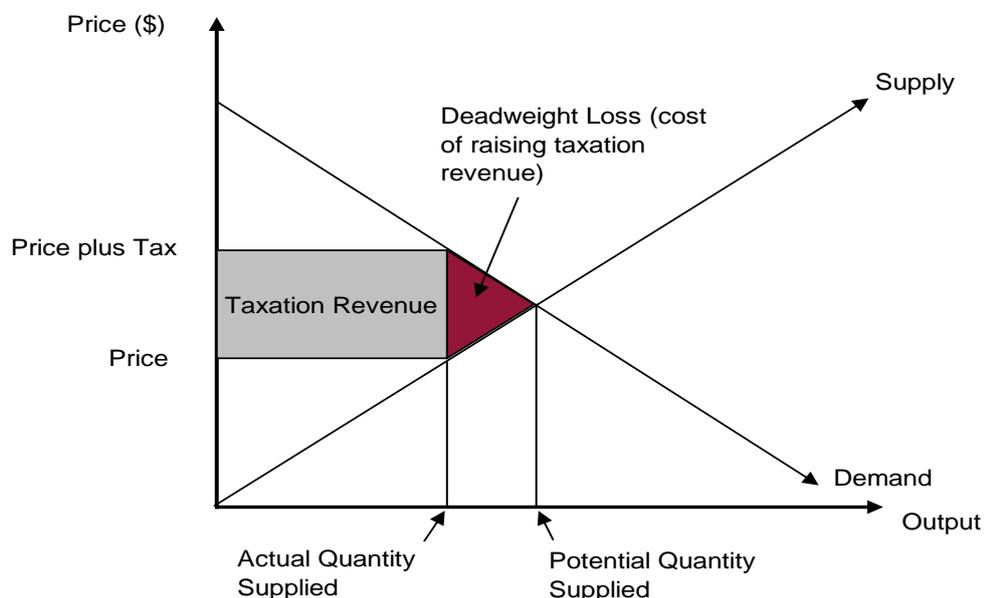
DWLs refer to the costs of administering welfare pensions and raising additional taxation revenues. Although invalid and sickness benefits and forgone taxation are transfers, not real costs (so should not be included in the estimation of total costs), it is still worthwhile estimating them as that helps us understand how the total costs of liver disease are shared between the taxpayer, the individual and other financiers.

There are two sources of lost tax revenue that result from the lower earnings – the potential income tax forgone and the potential indirect (consumption) tax forgone. The latter is lost because, as income falls, so does consumption of goods and services. The average personal income tax rate used is 21.8% and the average indirect taxation rate used is 11.1%, based on parameters for 2012 from the Deloitte Access Economics macroeconomic model.

Transfer payments (Government payments/services and taxes) are not a net cost to society as they represent a shift of consumption power from one group of individuals to another in society. If the act of taxation did not create distortions and inefficiencies in the economy, then transfers could be made without a net cost to society. However, through these distortions, taxation does impose a DWL on the economy.

DWL is the loss of consumer and producer surplus, as a result of the imposition of a distortion to the equilibrium (society preferred) level of output and prices. Taxes alter the price and quantity of goods sold compared to what they would be if the market were not distorted, and thus lead to some diminution in the value of trade between buyers and sellers that would otherwise be enjoyed (Figure 5.1).

Figure 5.1: DWLs of taxation



The rate of DWL used in this report is 27.5 cents per \$1 of tax revenue raised plus 1.25 cents per \$1 of tax revenue raised for Australian Taxation Office administration, based on Productivity Commission (2003) in turn derived from Lattimore (1997), i.e. 28.75% overall. The total extra tax dollars required to be collected include:

- the taxation revenue lost as a result of the impact of liver disease on the employment rates of those affected; and
- the additional induced social welfare payments required to be paid.

5.5.2.2 Lost taxation

Reduced earnings due to reduced workforce participation, absenteeism and premature death also have an effect on taxation revenue collected by the Government. As well as forgone income (personal) taxation, there will also be a fall in indirect (consumption) tax, as those with lower incomes spend less on the consumption of goods and services.

Personal income tax forgone is a product of the average personal income tax rate (21.8%) and the forgone income. With liver disease and lower income, there will be less consumption of goods and services, with the indirect taxation rate estimated as 11.1%.

These average taxation rates are derived for 2012 from the Deloitte Access Economics macroeconomic model. Together these calculations generate an expected total loss of tax revenue of approximately \$1.464 billion in 2012.

Using the rate of DWL at 28.75%, the DWLs of associated costs such as lost taxation and welfare transfers are estimated to be \$527 million.

5.6 Summary of other financial costs

In total, the non-health related financial costs, including costs associated with productivity losses, are estimated to be \$5.0 billion in 2012 in Australia.

Table 5.9: Summary of other financial costs

Other financial costs	2012 (\$ million)
Productivity losses:	
Employment	\$2,067.2
Absenteeism	\$207.1
Premature death	\$1,914.6
Carers	\$258.7
Program payments:	
NRCP	\$0.3
Palliative care	\$1.6
Funeral costs	\$33.9
DWL	\$526.8
Total financial costs	\$5,010.2

Note: Total may not equal the sum of the parts due to rounding.

6 Burden of disease

6.1 Methodology

Deloitte Access Economics has adopted 'burden of disease' methodology in order to quantify the impact of liver disease on wellbeing. The approach is non-financial, where pain, suffering and premature mortality are measured in terms of Disability Adjusted Life Years (DALYs), with 0 representing a year of perfect health and 1 representing death.

6.1.1 Valuing life and health

The burden of disease as measured in DALYs can be converted into a dollar figure using an estimate of the **Value of a 'Statistical' Life** (VSL). As the name suggests, the VSL is an estimate of the value society places on an anonymous life. Since Schelling's (1968) discussion of the economics of life saving, the economic literature has focused on **willingness to pay** (WTP) – or, conversely, willingness to accept – measures of mortality and morbidity, in order to develop estimates of the VSL.

Estimates may be derived from observing people's choices in situations where they rank or trade off various states of wellbeing (loss or gain) either against each other or for dollar amounts e.g. stated choice models of people's WTP for interventions that enhance health or willingness to accept poorer health outcomes or the risk of such states. Alternatively, risk studies use evidence of market trade-offs between risk and money, including numerous labour market and other studies (such as installing smoke detectors, wearing seatbelts or bike helmets and so on).

The extensive literature in this field mostly uses econometric analysis to value mortality risk and the 'hedonic wage' by estimating compensating differentials for on-the-job risk exposure in labour markets; in other words, determining what dollar amount would be accepted by an individual to induce him/her to increase the probability of death or morbidity by a particular percentage. Viscusi and Aldy (2002), in a summary of mortality studies, found the VSL ranged between US\$4 million and US\$9 million with a median of US\$7 million (in year 2000 US dollars), similar but marginally higher than the VSL derived from studies of US product and housing markets. They also reviewed a parallel literature on the implicit value of the risk of non-fatal injuries.

Weaknesses in the WTP approach, as with human capital approaches to valuing life and wellbeing, are that there can be substantial variation between individuals. Extraneous influences in labour markets such as imperfect information, income/wealth or power asymmetries can cause difficulty in correctly perceiving the risk or in negotiating an acceptably higher wage in wage-risk trade off studies, for example.

As DALYs are enumerated in years of life rather than in whole lives it is necessary to calculate the **Value of a ‘Statistical’ Life Year (VSLY)** based on the VSL. This is done using the formula:²⁴

$$VSLY = VSL / \sum_{i=0, \dots, n-1} (1+r)^i$$

Where: n = years of remaining life, and
 r = discount rate

Clearly there is a need to know n (the years of remaining life), and to determine an appropriate value for r (the discount rate). There is a substantial body of literature, which often provides conflicting advice, on the appropriate mechanism by which costs should be discounted over time, properly taking into account risks, inflation, positive time preference and expected productivity gains.

Access Economics (2008b) recommended an average VSL of \$6.0 million in 2006 Australian dollars (\$3.7 million to \$8.1 million). This equates to an average VSLY in 2006 of \$252,014 (\$155,409 to \$340,219), using a discount rate of 3% over an estimated 40 years remaining life expectancy. However, from this gross value, Deloitte Access Economics deducts all costs borne by the individual, reflecting the source study VSL estimates, to avoid double counting. This provides a different net VSLY for different conditions (and for different age-gender groups).

Since Access Economics (2008b) was published, the Department of Finance and Deregulation (2008) has also provided an estimate of the VSLY, which appears to represent a fixed estimate of the net VSLY. This estimate was \$151,000 in 2007, which inflates to \$187,741 in 2012 dollars. This estimate is used for modelling calculations in this report.

6.1.2 Burden of disease due to liver disease

6.1.2.1 Disability weights

Disability weights (DWs) were drawn from Victorian Department of Human Services (2005) and Begg et al (2007) which were in turn drawn from international studies. Table 6.1 indicates the list of DWs that are relevant to this study.

Table 6.1: Relevant disability weights in the literature

Disease type	DW	Comments
<u>Hepatitis A:</u>		
Uncomplicated episodes	0.093	GBD age-specific weights, average shown here
Complicated episodes	0.420	Dutch weight for complicated episode (50%) plus GBD weight for uncomplicated episode (50%)
Prolonged or relapsing episodes	0.140	Dutch weight for mild depression

²⁴ The formula is derived from the definition:
 $VSL = \sum VSLY_i / (1+r)^i$ where $i=0, 1, 2, \dots, n$
 where VSLY is assumed to be constant (i.e. no variation with age).

Disease type	DW	Comments
<u>Hepatitis B:</u>		
Acute symptomatic episodes	0.210	Dutch weight
Chronic symptomatic carrier	0.360	Dutch weight
Compensated liver cirrhosis	0.310	Dutch weight
Decompensated liver cirrhosis	0.840	Dutch weight
<u>Hepatitis C:</u>		
Acute symptomatic episodes	0.210	Dutch weight for hepatitis B
Chronic symptomatic carrier	0.360	Dutch weight for hepatitis B
Decompensated liver cirrhosis	0.840	Dutch weight
<u>Primary liver cancer:</u>		
Diagnosis and initial treatment	0.430	Dutch weight for colorectal cancer
State after intentionally curative primary therapy	0.200	Dutch weight for colorectal cancer
Clinically disease free	0.200	Dutch weight for colorectal cancer
Irradically removed/disseminated/preterminal	0.830	Dutch weight for colorectal cancer
Terminal phase	0.930	Dutch weight for end-stage disease
<u>Other:</u>		
Cirrhosis of the liver	0.339	GBD weight

Source: Victorian Department Human Services (2005) and Begg et al (2007).

To estimate the years of healthy life lost due to disability (YLDs) for liver disease, the following approach was taken to determine the disability weights to be used for each disease category.

- For hepatitis A, the average of the DWs for uncomplicated, complicated, prolonged and relapsing episodes is used, i.e. 0.218, but only applied for one month duration.
- For hepatitis B, the average of the DWs for acute symptomatic episodes and chronic symptomatic carrier is used, i.e. 0.285.
- For hepatitis C, as per hepatitis B, the average of the DWs for acute and chronic acute symptomatic episodes and chronic symptomatic carrier is used, i.e. 0.285. However, according to Law et al (2003), the number of hepatitis C-related cirrhosis cases was estimated to be around 6,500 in Australia in 2001. Inflating this number using the average per annum population growth rate of 1.5% between 2001 and 2012, it is estimated that the number of hepatitis C-related cirrhosis is 7,495 in 2012. Separating this from the total number of prevalence cases in Australia for hepatitis C, the DW for cirrhosis of the liver, 0.339, is used to estimate the YLDs for these hepatitis C-related cirrhosis cases (see final dot-point below).
- For primary liver cancer, the average of the DWs for diagnosis and initial treatment, state after intentionally curative, primary therapy, clinically disease free, irradically removed/disseminated/preterminal, and terminal phase is used, i.e. 0.518.
- For the remaining liver diseases (i.e. ALD, PSC, PBC and NAFLD), the DW for cirrhosis of the liver is applied to the 17,266 people estimated to have progressed to cirrhosis. This included all the ALD (6,203), PBC (433) and PSC (872) cases, plus the cases of cirrhosis from hepatitis C (7,495 as above) and, as noted in section 5.1.1 for productivity losses,

NAFLD-related cirrhosis (2,264 i.e. assumed to be the same as the number of NAFLD deaths). Haemochromatosis is assumed to have no impact on loss of wellbeing.

Together with the estimate of years of life lost due to premature death (YLLs), an estimate of DALYs is then obtained. Multiplying the total number of DALYs by the VSLY in 2012 provides an estimate of the dollar value loss of wellbeing from liver disease.

6.2 Findings

6.2.1 YLDs

Based on the DWs outlined above and the total number of people experiencing symptomatic liver disease (529,376 as estimated in the previous section), the YLDs for liver disease has been calculated for the 2012 (Table 6.2)

Table 6.2: Estimated YLD for liver disease, 2012

Type	YLDs
Primary liver cancer	752
Hepatitis	145,536
Other	5,853
Total	152,141

Note: The YLLs for Hepatitis C-related cirrhosis is included in the other category due to a different DW applied.

Source: Deloitte Access Economics calculations.

6.2.2 YLLs

Together with the number of deaths as indicated in Section 2, (1,270 deaths due to primary liver cancer, 2,550 deaths due to hepatitis C, 2,264 deaths due to NAFLD or ALD) YLLs have been estimated based on the age-gender distribution of deaths by the corresponding YLLs for the age of death in the Standard Life Expectancy Table (West Level 26) with a discount rate of 3% and no age weighting. Deaths associated with hepatitis B and PBC have been excluded to avoid double counting. The estimated YLLs are presented in Table 6.3.

Table 6.3: Estimated YLLs for liver disease, 2012

Type	YLLs
Primary liver cancer	15,024
Hepatitis	39,608
Other	34,283
Total	88,914

Note: The YLDs for Hepatitis B and PSC are included under primary liver cancer.

Source: Deloitte Access Economics calculations.

6.2.3 DALYs

The overall loss of wellbeing due to liver disease is illustrated in the following table.

Table 6.4: Estimated DALYs for liver disease, 2012

Type	DALYs
Primary liver cancer	15,776
Hepatitis	185,144
Other (i.e. PBC, PSC and ALD)	40,136
Total	241,055

See notes as indicated in Table 6.2 and Table 6.3.

Source: Deloitte Access Economics calculations.

Multiplying the number of DALYs by the VSLY (i.e. \$187,741) provides an estimate of the dollar value of the loss of wellbeing due to liver disease in 2012.

In 2012, the estimated cost resulting from lost wellbeing from primary liver cancer, hepatitis, and other liver diseases is estimated to be approximately \$45.3 billion.

7 Interventions and initiatives

This chapter conducts breakeven analyses (i.e. the point at which cost and benefit equate to each other) of two potential initiatives which aim to reduce the burden of liver disease. Namely an educational program to raise awareness, and a nurse-led community based model of care for liver diseases. Separately, this chapter also evaluates the cost effectiveness of a primary liver cancer screening program in the Australian context.

7.1 Educational programs

7.1.1 Brief description

In consultation with GESA, Deloitte Access Economics has modelled this intervention as a potential initiative that could be introduced through collaboration between Medicare Locals, GESA/ALA to develop a GESA-led educational program. This program would aim to increase awareness of chronic liver disease and complications arising from liver disease amongst GPs as well as in communities at high risk of developing chronic liver disease. The program would be structured around the following important aspects to increase awareness nationwide.

- **Preventative measures:** These could include hepatitis B vaccination, increase awareness of risks of excess alcohol intake, controlling risk factors for type II diabetes mellitus, hypercholesterolaemia and obesity amongst those patients who are at risk of developing NAFLD.
- **Screening:** The screening of patients at risk of contracting chronic liver disease, such as chronic hepatitis B and C, haemochromatosis, liver cancer and those with metabolic disease (increased BMI, type II DM, hyperlipidemia, cardiovascular diseases) for NAFLD. This could allow for early detection and treatment.
- **Potential complications:** Similarly to the above, initiation of strategies to prevent complications related to liver disease could lead to earlier and more efficacious treatment.

7.1.2 Potential cost

The cost or funding associated with the above potential initiative has been based on the cost of a similar initiative, the National Perinatal Depression Initiative (NPDI). While the NPDI is an initiative that targets a mental health area, the framework and activities of NPDI are similar to the proposed initiative by GESA.

Specifically, the aim of NPDI is to improve the prevention and early detection of antenatal and postnatal depression, and to provide better care, support and treatment for expectant and new mothers experiencing perinatal depression. The activities under this initiative include workforce training and development, routine and universal screening, treatment, care and support, and community awareness. In 2008, the federal government committed \$30 million over five years to the states and territories towards this initiative (Government of Western Australia Department of Health, 2008).

Assuming similar funds are granted to the GESA-led initiative, the average cost of such an initiative per year could be around \$6 million. Therefore, to achieve a breakeven point, the initiative would be required to achieve a cost saving (benefit) of similar magnitude.

7.1.3 Potential saving/benefit

As estimated in this study, the total financial costs associated with liver diseases are estimated to be \$5.4 billion in 2012, which is made up largely of health system costs and productivity losses. Dividing this figure by the number of Australians with symptomatic liver disease translates to an average financial cost of \$10,251 per person in 2012. The number of people with symptomatic liver disease was estimated from the burden of disease calculations (Section 6.1.2) as 529,376 people based on the symptomatic prevalent cases of primary liver cancer, hepatitis B and C, one twelfth of people with hepatitis A (i.e. assuming average duration of one month), and people with other liver conditions who were estimated to have progressed to cirrhosis

Assuming the cost per annum for GESA-led initiative to be \$6 million (section 7.1.2), and dividing this by the financial cost per symptomatic person, the breakeven point occurs when the introduction of the initiative is associated with a reduction in the number of people with symptomatic liver disease by 585 people each year. 585 people is 0.11% of the target population with symptomatic liver disease.

Assuming a cost of \$6 million per annum, a GESA-led educational initiative can achieve its breakeven point if the introduction of the initiative is associated with a reduction of 585 symptomatic cases of liver disease per year.

7.2 Nurse-led community based care model

7.2.1 Brief description

The second potential initiative is a collaboration between GESA, the Gastroenterological Nurses' College of Australia, and the Australasian Hepatology Association to develop and implement a nurse-led community based model of care, which is supported and linked to a hospital based liver centre aimed at:

- preventing the progression of liver diseases, screening for complications of liver diseases and admission avoidance by early detection and treatment of complications related to liver diseases;
- assisting with community based screening programs for primary liver cancer;
- linking patients with alcohol related liver disease with drug and alcohol services; and
- linking patients with liver diseases with Medicare Locals and multidisciplinary liver disease teams in tertiary institutes for services such as nutritional support for those with advanced liver diseases, and lifestyle modifications for those with NAFLD including drug and alcohol services.

7.2.2 Potential cost

As in section 7.1.2, it is necessary to utilise the cost of similar models to proxy for a nurse-led community based care model for liver diseases. In 2010, Parkinson's Australia proposed that:

“the Federal Government provide funding to employ 200 Specialist Neurological Nurse Educators across Australia to significantly improve the quality of life for people with Parkinson's Motor Neurone Disease and other neurological conditions whilst reducing government health care costs. These nurse educators can substitute for some of the specialist care, contribute to better management of treatment, and through information and referrals reduce the impact of symptoms, and hospital and aged care admissions ” (Parkinson's Australia, 2010).

According to Parkinson's Australia (2012), it was envisaged that an initial 50 specialist nurses could be established at a cost \$7.5m per year, i.e. \$30m over 4 years. Consequently, assuming that the nurse-led community based model for liver diseases would cost a similar amount, it would be necessary to achieve a similar magnitude of saving/benefit to break even.

7.2.3 Potential saving/benefit

The potential benefit associated with a successful nurse-led community based model for liver diseases is associated less with prevention of the condition and early intervention (as in the first initiative, where all financial costs would be saved), but more with preventing complications from the condition. As such, the potential benefits assume that the patient would still incur health system costs but would not suffer the productivity or other financial costs associated with liver disease. The total financial cost excluding health expenditures are associated with productivity losses has been estimated at \$5.0 billion in 2012, or approximately \$9,435 per person with liver disease. Assuming the cost per annum for nurse-led community based care model for liver diseases to be \$7.5 million (section 7.2.2) and dividing this by the savings per person (\$9,435), the breakeven point occurs when the introduction of a nurse-led community based care model for liver diseases keeps 732 people with liver disease healthy and at working at average workforce participation rates each year. 732 people is 0.14% of the target population with symptomatic liver disease.

Assuming a cost of \$7.5 million per annum, a nurse-led community based care model for liver diseases would achieve its breakeven point if it led to at least 732 people with liver disease improving their productivity to be on par with that of the general Australian population.

7.3 Liver cancer screening program

7.3.1 Brief description

Around 1,200 Australians are expected to die from liver cancer in 2012 (AIHW 2011, ABS 2008). Amin et al (2007) found around 30% of liver cancer was associated with hepatitis B

and/or C infection. Liver cirrhosis (often alcohol induced) is another risk factor. The Cancer Institute of NSW estimates a five year survival of 17% for men with liver cancer and 15% for women.²⁵ Liver cancer is often asymptomatic in the early stages of the disease. A screening program for high risk individuals may detect the cancer earlier and enable effective treatment to be implemented.

7.3.2 The eligible patient population

Zhang et al (2004) and Qian et al (2010) evaluated liver cancer screening programs in China and Australia respectively. The two programs offered the same basic screening tests - a six monthly alpha fetoprotein blood test and ultrasound. The populations screened differed slightly, the Australian study included all patients attending a tertiary treatment facility in Victoria for liver cirrhosis and all male (non-cirrhotic) patients with chronic hepatitis B aged over 40 years. The Chinese study invited adults aged 35 to 59 years with hepatitis B infection or a history of chronic hepatitis infection.

The screening population considered in this analysis was all Australians with liver cirrhosis, and non-cirrhotic hepatitis B positive males aged 40 years and above. This equates to 68,793 people in 2012.²⁶

7.3.3 The screening tests

It is expected the liver cancer screening program would become standard and clinicians would perform the (at least initial) diagnostic test on all eligible patients as part of routine care. Compliance with six monthly testing is assumed given such patients would most likely need to return to their cirrhosis or hepatitis B treatment clinic for check-ups at these time points, or more frequently. The cost of primary and secondary screening tests required for the program was sourced from Qian et al (2010) and inflated for the expected screening population and health inflation to 2012 based on the consumer price index (ABS 2012a). The result for a six year screening period was \$1,395 per patient in 2012.

7.3.4 Detection of liver cancer

Qian et al (2010) reported a liver cancer detection rate of 2.7% per year (amongst the screened population), or 8.2% patients over the entire six year study. Three quarters of the detected cancers were deemed curable and of those diagnosed with liver cancer, 45% were alive at the end of follow up (after receiving treatment).

Without the early screening program liver cancer is likely to be detected in the later stages of the disease, when treatment is less effective. The current average five year survival rate for those diagnosed with liver cancer in the general population is 16%²⁷ making participants

²⁵ <http://www.cancerinstitute.org.au/cancer-in-nsw/cancer-facts/liver-cancer>

²⁶ The prevalence of liver cirrhosis in Australia in 2012 was estimated at 4,030 based on AIHW prevalence data (Begg et al 2007) and population projections (ABS 2008). There are 65,448 males aged 40 years and above with hepatitis B (section 2.2.2). The Victorian Government Department of Human Services (2005) estimated that of those hospitalised for cirrhosis, 17% had hepatitis B. Applying this percentage brings about a total screening population estimate of 68,793.

²⁷ <http://www.cancerinstitute.org.au/cancer-in-nsw/cancer-facts/liver-cancer>

in the screening program almost three times (2.8) more likely to survive following a cancer diagnosis.

The life years gained as a result of the screening program was estimated by finding the difference between the average age at diagnosis (amongst the cured group in the Qian et al (2010) and the Australian median age of death for males (ABS 2012b)²⁸. The average life years gained (22 years) was then multiplied by the marginal number of expected cured patients as a result of the screening program.

7.3.5 Cost effectiveness

The cost effectiveness of the screening program was estimated by dividing the cost of the screening program by the life years gained over six years.

Table 7.1: Parameters for cost effectiveness analysis of liver cancer screening program, 2012

Parameter	
Number of eligible patients	68,793
Estimated cost of screening tests	\$95.96 million
Marginal number of liver cancers detected	1,663
Life years gained	36,261
Cost per life year gained	\$2,646

The liver cancer screening program described here is highly cost effective amongst patients with cirrhosis and males with hepatitis B. The program could be extended to include hepatitis C positive patients or those with family history of HCC in HBV irrespective of gender. Currently available literature did not allow this patient group to be included in the analysis.

²⁸ 90% patients cured in Qian et al (2010) study were male

8 Conclusions

8.1 Summary of findings

Our findings show that NAFLD is the most prevalent liver disease in Australia with an estimated 5.5 million Australians affected, including 40% of all adults aged 50 years and above. NAFLD was associated with the highest number of deaths (2,264 estimated for 2012). The mortality of primary biliary cirrhosis and haemochromatosis that is medically managed were considered to be on par with that of the general Australian population.

The total financial cost of liver diseases in Australia in 2012 was estimated as \$5.44 billion (Table 8.1). If the burden of disease is included, valued at \$45.3 billion, then the total socioeconomic impact of liver diseases is \$50.7 billion.

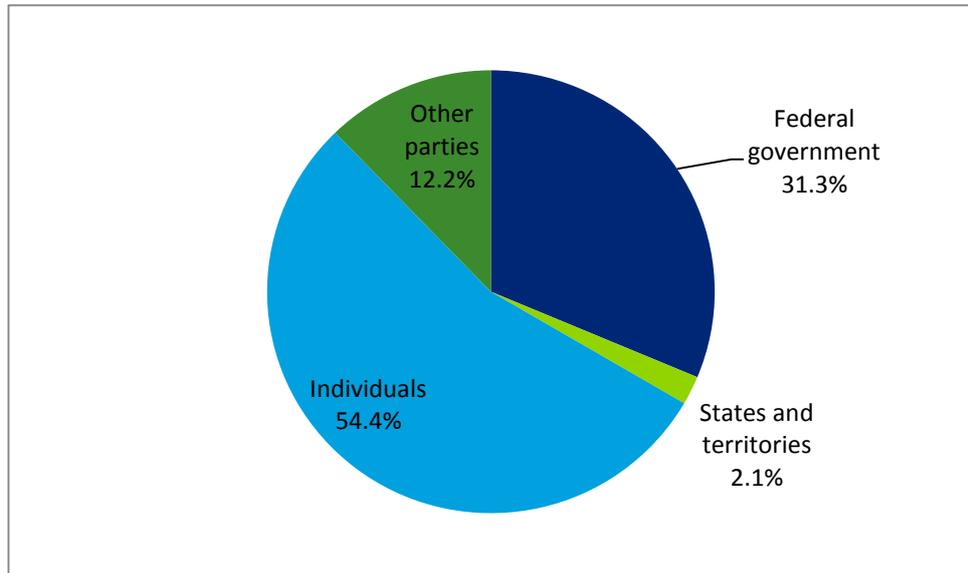
- The majority (i.e. 54%) of the financial costs are borne by individuals, mainly through lost earnings. If the value of healthy life lost (burden of disease) is included, then the total share of costs borne by individuals rises to 95%.
- The Australian Government is the second largest bearer of the financial costs of liver diseases, namely \$1.7 billion (31%). This is mostly from taxation revenue forgone because of productivity impacts, as well as funding health system expenditure, program and welfare payments.
- Lost productivity accounts for 82% of financial costs (\$4.4 billion, including lost carer productivity). If non-financial costs are included, the burden of disease accounts for 89% of total costs.
- Deadweight losses (mainly from lost taxation) are the second largest cost by type.

Table 8.1: Total costs, by type and bearer, 2012 (\$ million)

	Federal government	States and territories	Individuals	Other parties	Total
<u>Burden of Disease</u>			45,256.0		45,256.0
<u>Health system costs</u>					
Health expenditure	164.9	102.0	70.7	48.7	386.2
National immunisation program	14.5	9.0	6.2	4.3	34.0
Research funding	5.0	3.1	2.1	1.5	11.7
<u>Productivity costs</u>					
Employment	680.3		1,386.9		2,067.2
Absenteeism	68.2			139.0	207.1
Premature death	630.1		1,284.5		1,914.6
<u>Carer costs</u>	85.1		173.5		258.7
<u>Program payments</u>					
National respite for carers	0.3				0.3
Palliative care	1.6				1.6
<u>Funeral costs</u>			33.9		33.9
<u>Welfare payments</u>	53.7			-53.7	-
<u>Transfer DWLs</u>				526.8	526.8
Total	1,703.7	114.1	48,213.8	666.6	50,698.1

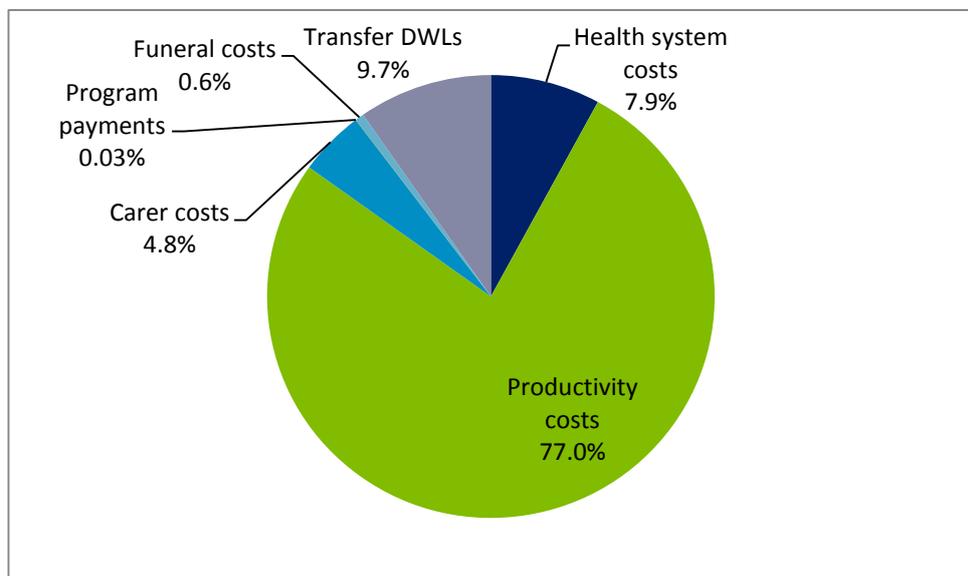
Source: Deloitte Access Economics calculations.

Chart 8.1: Distribution of total financial costs by bearer, 2012



Source: Deloitte Access Economics calculations.

Chart 8.2: Distribution of financial costs by type, 2012



Source: Deloitte Access Economics calculations.

8.2 Comparisons

Deloitte Access Economics has previously estimated the costs of other highly prevalent chronic conditions including:

- type 2 diabetes – see Access Economics 2008a;
- chronic kidney disease associated with diabetes – see Access Economics 2011; and
- cardiovascular diseases (which comprise a range of conditions including heart attack and stroke) – see Access Economics 2005.

The costs for diabetes, chronic kidney diseases and cardiovascular diseases were inflated to 2012 using appropriate price inflators to account for unit cost changes and population growth between the year of each study and 2012. Table 8.2 presents the economic costs of Type 2 diabetes, chronic kidney diseases and cardiovascular diseases.

Table 8.2: Comparison with other diseases, 2012 (\$ million)

	Type 2 Diabetes	Chronic kidney diseases ^(b)	Cardiovascular diseases	Liver diseases
BoD	\$22,182.0	\$679.8	\$113,715.8	\$45,256.0
Health System	\$1,261.0	\$516.3	\$5,717.3	\$431.9
Productivity	\$4,920.0	\$72.6	\$5,143.8	\$4,188.9
Carers	\$5,328.0	\$42.9	\$3,342.4	\$258.7
DWL	\$838.0	\$108.9	\$1,703.3	\$526.8
Other financial	\$77.0	\$3.8	\$0.0	\$35.8
Total financial	\$12,424.0	\$744.5	\$15,906.7	\$5,442.1
Total incl. BoD	\$34,606.0	\$1,424.4	\$129,622.5	\$50,698.1

Source: Access Economics (2005), Access Economics (2008a), Access Economics (2011), and Deloitte Access Economics' calculations.

The total estimated economic cost of liver diseases was higher than that of Type 2 diabetes – indeed, liver disease is approximately 40% more costly than Type 2 diabetes and chronic kidney diseases²⁹ combined. Liver disease is about 39% of the cost of cardiovascular disease, which is one of the most costly conditions in Australia (as is cancer).

8.3 Interventions and recommendations

Deloitte Access Economics, with close consultation with GESA, conducted two breakeven analyses for two potential initiatives to reduce liver disease, a GESA-led education program to increase awareness of chronic liver diseases and a nurse-led community based care model for liver diseases.

- Assuming a cost of \$6 million per annum, a GESA-led educational initiative can achieve its breakeven point if the introduction of the initiative is associated with a reduction of 585 symptomatic cases of liver disease per year.
- Assuming a cost of \$7.5 million per annum, a nurse-led community based care model for liver diseases would achieve its breakeven point if it led to at least 732 people with liver disease improving their productivity to be on par with that of the general Australian population.

A cost effectiveness analysis was also conducted for a liver cancer screening program. This program was found to be highly cost effective amongst patients with cirrhosis and males with hepatitis B. The cost per life year gained estimated was \$2,646 in 2012.

²⁹ Note that the costs associated with chronic kidney diseases in this case only relate to individuals with Type 2 diabetes.

Recommendations

Based on the difficulties encountered in collating data for this project, it is recommended that national database for sub entities of chronic liver disease is established, in without duplicating the data collated by the Kirby Institute but, rather, potentially collaborating in relation to the datasets collated by that Institute.

In line with the educational program outlined in section 7.1, it is recommended that a pilot project is conducted through collaboration between a Medicare Local and GESA/ALA to establish a model liver clinic that delivers multidisciplinary care to patients with chronic liver disease – focussing on GP, patient and family education, treatment of the disease and prevention of liver disease progression, nutritional support to prevent complications related to over- or under-nutrition (particularly in cirrhotics who develop severe cashexia), social support, and links to drug and alcohol services. The pilot could also utilise technology, such as tele-health, to link outreach communities with the liver clinic.

In line with the nurse-led community based care model outlined in section 7.2, it is recommended that a pilot project is conducted through collaboration between GESA, the Gastroenterological Nurses' College of Australia, and the Australasian Hepatology Association to establish a nurse-led community based model of care run in the community from a hospital based liver centre.

In line with the liver cancer screening program for high risk individuals outlined in section 7.3, it is recommended that a trial screening program – a six monthly alpha fetoprotein blood test and ultrasound – is introduced for the approximately 70,000 Australians who have liver cirrhosis or who are 40+ males with non-cirrhotic hepatitis B.

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