



PARLIAMENT OF NEW SOUTH WALES

LEGISLATIVE COUNCIL

STANDING COMMITTEE ON SOCIAL ISSUES

**HEPATITIS C:**  
**THE NEGLECTED EPIDEMIC**

INQUIRY INTO  
HEPATITIS C IN NEW SOUTH WALES

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The functions of the Standing Committee on Social Issues are to inquire into, consider, and report to the Legislative Council on:

- any proposal, matter or thing concerned with the social development of the people in all areas of New South Wales;
- the equality of access to the services and benefits including health, education, housing and disability services provided by the Government and non-Government sector to the people in all areas of New South Wales;
- recreation, gaming, racing and sporting matters; and
- the role of Government in promoting community services and the welfare of the people in all areas of New South Wales.

Matters for inquiry may be referred to the Committee by resolution of the Legislative Council, a Minister of the Crown, or by way of relevant annual reports and petitions. The Committee has the legislative power to:

- summons witnesses;
- make visits of inspection within Australia;
- call upon the services of Government organisations and their staff, with the consent of the appropriate Minister;
- accept written submissions concerning inquiries from any person or organisation; and
- conduct hearings.

# TERMS OF REFERENCE

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That the Standing Committee on Social Issues inquire into, and report on, the incidence and impact of Hepatitis C in New South Wales, and in particular:

- a. the social and economic impact of Hepatitis C in New South Wales and the implications for future policy and funding of health and community services;
- b. the extent of the disease and its aetiology and epidemiology;
- c. the adequacy of policies, and diagnostic and treatment services with particular attention to strategies for prevention, given current health budget constraints;
- d. the groups and individuals in the community at increased risk of infection;
- e. the extent of the infection in specific population groups at risk, and the adequacy of education/prevention and care and treatment services available to them; and
- f. the risks involved for health care workers and the adequacy of policies and procedures on occupational health and safety.

**H**epatitis C people are in every part of our community. I've been a lecturer in tertiary education; a professional playwright and a freelance actor in theatre, television and film. I'm a grandfather; a devoted father of three adult children and one half of a long standing, loving partnership. I don't think I'm particularly different. I just happen to have Hepatitis C .

Help us beat it.

An extract from a personal submission received by the Inquiry

# TABLE OF CONTENTS

---

• CHAIR'S FOREWORD .....	I
• HEPATITIS C - AT A GLANCE .....	III
• GLOSSARY .....	V
• KEY CONCLUSIONS .....	IX
• EXECUTIVE SUMMARY .....	XI
• SUMMARY OF RECOMMENDATIONS .....	XV

## CHAPTER ONE:

<b>INTRODUCTION .....</b>	<b>1</b>
<b>1.1 Background to the Report .....</b>	<b>3</b>
<b>1.2 Putting this Inquiry into Context: Previous Work .....</b>	<b>4</b>
1.2.1 Federal Inquiries .....	4
• The Joint National Health and Medical Research Council and Australian Health Ministers' Advisory Council Taskforce: 1993 .....	4
• The National Hepatitis C Action Plan: 1994 .....	5
• Health and Medical Research Council Strategy for the Detection and Management of Hepatitis C in Australia: 1997 .....	9
• Australian National Council on AIDS and Related Diseases .....	10
1.2.2 State Initiated Taskforces .....	12
<b>1.3 Structure of the Report .....</b>	<b>13</b>

## CHAPTER TWO: A PROFILE OF HEPATITIS C .....

17

<b>2.1 The Hepatitis C Virus .....</b>	<b>19</b>
2.1.1 Aetiology .....	19
• The Chiron Patent .....	19
2.1.2 Transmission of the Hepatitis C Virus .....	20
2.1.3 Natural History of Hepatitis C .....	23
• Acute Hepatitis C .....	23
• Chronic Hepatitis C .....	23
2.1.4 Clinical Features of the Disease .....	25
2.1.5 Genotypes of the Hepatitis C Virus .....	26
2.1.6 Other Forms of Hepatitis .....	27

2.1.7	HIV and HCV: Contrasting Epidemics	29
	• Modes of Transmission	29
	• Natural History	30
	• Population Groups	30
	• Incidence and Prevalence Rates	31
	• Community (and Political) Response	32
	• Conclusion	33
<b>2.2</b>	<b>Epidemiology</b>	<b>33</b>
2.2.1	Prevalence of Hepatitis C	35
	• Prevalence of Hepatitis C in Australia	35
	• Prevalence of Hepatitis C in NSW	37
2.2.2	Incidence of Hepatitis C	38
	• Incidence of Hepatitis C in Australia	38
	• Incidence of Hepatitis C in NSW	39
2.2.3	Estimates of the Long-term Sequelae of Hepatitis C Infection	40
2.2.4	Notification of Hepatitis C	44
	• Notification of Hepatitis C in Australia	46
	• Notification of Hepatitis C in New South Wales	48
2.2.5	Conclusion	53
<b>2.3</b>	<b>Conclusion</b>	<b>54</b>

### CHAPTER THREE:

	<b>GROUPS AT RISK AND EXTENT OF INFECTION IN THESE GROUPS</b>	<b>55</b>
<b>3.1</b>	<b>Injecting Drug Users</b>	<b>57</b>
3.1.1	Prevalence of Hepatitis C amongst Injecting Drug Users	59
3.1.2	Prevalence of Hepatitis C amongst NSW Injecting Drug Users	62
3.1.3	Incidence of Hepatitis C amongst Injecting Drug Users	62
3.1.4	Incidence of Hepatitis C amongst NSW Injecting Drug Users	64
<b>3.2</b>	<b>Prisoners</b>	<b>68</b>
3.2.1	Prevalence of Hepatitis C in Prisons	69
3.2.2	Prevalence of Hepatitis C in the NSW Prisons System	69
3.2.3	Incidence of Hepatitis C in Prisons	71
3.2.4	Incidence of Hepatitis C in NSW Prisons System	71
3.2.5	Injecting Drug Users in Prisons	74
3.2.6	Rates of Hepatitis C amongst Prisoners who Inject Drugs	77
3.2.7	Tattooing in Prisons	78
3.2.8	Tattooing in the NSW Corrections System	80
3.2.9	Conclusion	80
<b>3.3</b>	<b>Recipients of Infected Blood and Blood Products</b>	<b>81</b>
<b>3.4</b>	<b>People Born Overseas</b>	<b>84</b>
<b>3.5</b>	<b>Health Care Workers and their Patients</b>	<b>85</b>
3.5.1	Transmission from Patient to Health Care Worker	85
3.5.2	Transmission from Health Care Worker to Patient	86
3.5.3	Transmission from Patient to Patient	87
<b>3.6</b>	<b>Mother-to-Child Transmission</b>	<b>89</b>



<b>3.7</b>	<b>Skin Penetration: Tattoos and Acupuncture</b>	<b>90</b>
<b>3.8</b>	<b>Other Modes of Transmission of Hepatitis C Transmission</b>	<b>91</b>
3.8.1	Sexual Transmission of HCV	91
3.8.2	Household or Intrafamilial Transmission of HCV	92
3.8.3	Unapparent Inoculation	92
3.8.4	Conclusion	92
<b>3.9</b>	<b>Conclusion</b>	<b>93</b>

**CHAPTER FOUR:**

	<b>THE SOCIAL AND ECONOMIC IMPACT OF HEPATITIS C</b>	<b>95</b>
<b>4.1</b>	<b>The Social Impact of Hepatitis C</b>	<b>97</b>
4.1.1	The Impact of the Virus' Physical and Psychological Symptoms	99
4.1.2	The Impact of the Disease on those with Medically Acquired HCV	101
	• Recipients of Infected Blood or Blood Products	101
	• Health Care Workers	102
4.1.3	The Impact on those Living in Rural Areas	102
4.1.4	The Impact of HCV on Parenting	103
	• Transmission	103
	• Family Issues	104
	• The Extended Family	105
4.1.5	Conclusion	106
<b>4.2</b>	<b>Discrimination and Stigmatisation Experienced by those with Hepatitis C</b>	<b>108</b>
4.2.1	Discrimination by Health Care Workers	109
	• Privacy Related Issues	113
4.2.2	Discrimination by the General Community	115
4.2.3	Discrimination Experienced by Injecting Drug Users with Hepatitis C	116
4.2.4	Conclusion	117
<b>4.3</b>	<b>The Economic Impact of HCV</b>	<b>120</b>
4.3.1	The Economic Impact on those with HCV	120
4.3.2	The Economic Impact of HCV on the Community as a Whole	122
<b>4.4</b>	<b>Implications of Social and Economic Impact upon Future Health Funding, Planning and Policy</b>	<b>123</b>
<b>4.5</b>	<b>Need for Further Research into the Social and Economic Impact of Hepatitis C</b>	<b>124</b>
<b>4.6</b>	<b>Conclusion</b>	<b>127</b>

**CHAPTER FIVE:**

	<b>HEPATITIS C POLICIES</b>	<b>129</b>
<b>5.1</b>	<b>Current Hepatitis C Policies</b>	<b>131</b>
<b>5.2</b>	<b>The Adequacy of These Policies: The Experts' Opinion</b>	<b>132</b>

<b>5.3</b>	<b>What is Policy?</b> .....	<b>135</b>
<b>5.4</b>	<b>Rectifying Current Policy Inadequacies</b> .....	<b>136</b>
5.4.1	Action at the Ministerial level: Office of the Minister for Health .....	137
5.4.2	Action at the Departmental Level: Central Agency - NSW Health .....	139
	• Development of a NSW Hepatitis C Policy Statement .....	139
	• Development of a Statewide Hepatitis C Strategic Plan .....	141
	• Adequate and Dedicated Hepatitis C Funding .....	142
	• Adequate and Appropriate Staffing: Central Agency .....	146
5.4.3	Action at the Regional Level: the Area Health Services .....	148
	• Development of Regional Hepatitis C Strategic Plans .....	148
	• Adequate and Appropriate Staffing: Area Health Services ...	149
<b>5.5</b>	<b>Conclusion</b> .....	<b>152</b>

## CHAPTER SIX

	<b>DIAGNOSING HEPATITIS C</b> .....	<b>153</b>
<b>6.1</b>	<b>Who Should be Tested?</b> .....	<b>155</b>
<b>6.2</b>	<b>Testing for Hepatitis C</b> .....	<b>156</b>
6.2.1	Antibody Tests .....	156
6.2.2	Antigen Detection .....	159
	• Qualitative Tests for HCV RNA .....	160
	• Quantitative Tests for HCV RNA .....	161
	• HCV Genotype Testing .....	161
<b>6.3</b>	<b>Laboratories</b> .....	<b>164</b>
6.3.1	Reference Laboratories .....	165
<b>6.4</b>	<b>Pre- and Post-test Counselling</b> .....	<b>168</b>
<b>6.5</b>	<b>Diagnosis of Prison Inmates</b> .....	<b>172</b>
6.5.1	Compulsory Hepatitis C Screening? .....	173
<b>6.6</b>	<b>Conclusion</b> .....	<b>174</b>

## CHAPTER SEVEN:

	<b>TREATING AND MANAGING HEPATITIS C: THE CURRENT SITUATION</b> .....	<b>175</b>
<b>7.1</b>	<b>Current Treatment Policies</b> .....	<b>177</b>
7.1.1	The National Interferon Data Base .....	179
<b>7.2</b>	<b>Available Treatment Options and Medical Procedures</b> .....	<b>180</b>
7.2.1	Interferon .....	180
	• Location of Interferon Prescribing Centres .....	180
	• Utilisation of Interferon Therapy .....	181
	• Efficacy of Interferon Therapy .....	182
	• Side Effects of Interferon Therapy .....	183
	• Contraindications to Interferon Therapy .....	185
	• The Cost of Interferon Therapy .....	186
	• The Cost Effectiveness of Interferon Therapy .....	187

•	Factors Predictive of a Beneficial Response to Interferon Therapy .....	188
•	Counselling on Interferon Therapy .....	189
•	Monitoring and Assessing the Efficacy of Interferon Therapy .....	190
7.2.2	Other Medications .....	191
•	Ribavirin .....	191
•	Protease Inhibitor Drugs .....	192
•	Ursodeoxycholic Acid .....	192
•	Corticosteroids .....	192
7.2.3	Liver Biopsies .....	192
7.2.4	Liver Transplants .....	192
7.2.5	Hepatocellular Carcinoma .....	193
7.2.6	Complementary Treatments and Therapies .....	193
7.2.7	Summary .....	195
<b>7.3</b>	<b>Treating and Managing Hepatitis C Positive Inmates in the State's Correctional System .....</b>	<b>196</b>
7.3.1	Treating Hepatitis C Positive Inmates .....	196
•	Liver Biopsies .....	197
•	Interferon Therapy .....	197
•	Inmates with Established Hepatitis C Related Diseases .....	198
7.3.2	Managing Hepatitis C Positive Inmates .....	198
<b>7.4</b>	<b>Conclusion .....</b>	<b>198</b>

**CHAPTER EIGHT:**

	<b>TREATING AND MANAGING HEPATITIS C: GETTING IT RIGHT .....</b>	<b>201</b>
<b>8.1</b>	<b>Inadequacies of Current Policies Regulating Treatment .....</b>	<b>203</b>
8.1.1	Policies Restricting Access to Treatment .....	203
•	National Interferon Database .....	215
•	Management of Patients not Receiving Interferon .....	216
8.1.2	Policies Limiting the Number of Interferon Prescribing Centres ...	217
8.1.3	Policies Limiting Pre-treatment Assessment .....	220
8.1.4	Policies Limiting Interferon Dosage Schedule .....	222
8.1.5	Policies Limiting Treatment Assessment and Monitoring .....	223
8.1.6	Policies Limiting PCR Testing for HCV+ Women Considering Pregnancy .....	224
<b>8.2.</b>	<b>Inadequacies of the Current Treatment Regime .....</b>	<b>225</b>
8.2.1	Limited Treatment Options .....	225
8.2.2	Limited Success of Available Therapy .....	226
8.2.3	Addressing Current Treatment Inadequacies .....	226
•	Need for Further Research .....	226
•	Need for Support for Those who do not Respond to Interferon .....	228
•	Need for Support for Those on Interferon .....	229
•	Liver Transplants .....	229

<b>8.3</b>	<b>Inadequacies of Current Service Delivery</b>	<b>230</b>
8.3.1	Inadequacies at the State and Health Area Level	231
8.3.2	Inadequacies at the Hospital Level	231
	• Waiting Lists	232
	• Inadequate Provision of Specialist Services	233
	• Inadequate Provision of Hepatitis C Clinical Nurses	234
	• Inadequate Allocation of Funding	235
8.3.3	Inadequacies at the General Practitioner Level	235
8.3.4	Conclusion	238
<b>8.4</b>	<b>Responding to Current Inadequacies</b>	<b>238</b>
8.4.1	Who Should Treat and Manage Hepatitis C?	241
	• Specialists and General Practitioners Working Together: Shared Care Project	242
	• A Greater Role for General Practitioners: The National Hepatitis C Education Program for General Practitioners	244
	• Training Those who Treat and Manage Hepatitis C	248
8.4.2	Where Should Hepatitis C be Treated and Managed?	249
	• the NSW Health Demonstration Projects	250
	• the Hepatitis C Coordinated Care Trial (HepCare)	253
8.4.3	Conclusion	255
<b>8.5</b>	<b>Treating Hepatitis C with Complementary Therapies</b>	<b>256</b>
<b>8.6</b>	<b>Difficulties Encountered in Treating and Managing Hepatitis C Positive Inmates in the State's Correctional System</b>	<b>256</b>
8.6.1	Treating and Managing the Disease	257
	• Limited Number of Health Care Professionals	258
	• Inmates' Diet	259
	• Lifestyle Unit	260
	• Post-release Care	261
8.6.2	Managing the Hepatitis C Treatment Regime	262
	• Limited Number of Inmates on Interferon	262
	• Difficulties in Administering Interferon within the Prisons System	262
	• Training Health Care Workers to Administer Interferon Therapy	263
	• Payment of Interferon	263
	• Length of Stay in Prison	265
	• Limiting Progress to Minimum Security Prisons	265
8.6.3	Managing the Side Effects of Hepatitis C and Interferon	265
	• Requests for Light Duties and Other Dispensations	266
	• Training Prison Officers to be Aware of Hepatitis C/ Interferon Side Effects	266
8.6.4	Proposed Model of Service Delivery	267
8.6.5	Providing Health Care within a Dual Discipline Framework	271
8.6.6	Conclusion	273

<b>8.7</b>	<b>Conclusion</b>	<b>274</b>
------------	-------------------	------------

**CHAPTER NINE:**

	<b>SUPPORTING THOSE WITH HEPATITIS C</b>	<b>275</b>
--	--	------------

<b>9.1</b>	<b>Community-based Organisations Supporting those with Hepatitis C</b>	<b>277</b>
------------	--	------------

9.1.1.	Hepatitis C Council of NSW	277
--------	----------------------------	-----

9.1.2	Supporting those with Medically Acquired Hepatitis C	281
-------	--	-----

•	Transfusion Related AIDS and Infectious Diseases Unit (TRAIDS)	281
---	--	-----

•	Haemophilia Foundation Australia	282
---	----------------------------------	-----

9.1.3	Supporting Injecting Drug Users with Hepatitis C	283
-------	--	-----

9.1.4	Conclusion	284
-------	------------	-----

<b>9.2</b>	<b>Support Groups</b>	<b>285</b>
------------	-----------------------	------------

<b>9.3</b>	<b>Financial Support to those with Hepatitis C</b>	<b>287</b>
------------	--	------------

9.3.1	Disability Support Pension	287
-------	----------------------------	-----

9.3.2	Financial Support to those with Medically Acquired Hepatitis C	289
-------	--	-----

<b>9.4</b>	<b>Community Support for those with Hepatitis C</b>	<b>291</b>
------------	---	------------

<b>9.5</b>	<b>Conclusion</b>	<b>293</b>
------------	-------------------	------------

**CHAPTER TEN:**

	<b>PREVENTING THE TRANSMISSION OF HEPATITIS C</b>	<b>295</b>
--	---	------------

<b>10.1</b>	<b>Preventing the Transmission of Hepatitis C Amongst Injecting Drug Users</b>	<b>299</b>
-------------	--	------------

•	A Profile of Injecting Drug Users	301
---	-----------------------------------	-----

•	Harm Minimisation	302
---	-------------------	-----

10.1.1	Preventative Strategies Currently in Place	303
--------	--	-----

•	Methadone Maintenance Therapy	304
---	-------------------------------	-----

•	Needle and Syringe Programs	308
---	-----------------------------	-----

•	Peer Based Education Among Injecting Drug Users	318
---	---	-----

10.1.2	Proposed Measures to Prevent or Delay Initial Injecting	320
--------	---	-----

•	Education	321
---	-----------	-----

•	Provision of Youth Services	324
---	-----------------------------	-----

10.1.3	Proposed Preventative Measures Targeting Injecting Drug Users	325
--------	---	-----

•	Hepatitis B Vaccination Program for Injecting Drug Users	325
---	--	-----

•	Treatment Options	326
---	-------------------	-----

•	Non-injecting Routes of Administration	327
---	--	-----

•	Drug Policy and Law Reform	330
---	----------------------------	-----

•	Safe Injecting Rooms	334
---	----------------------	-----

•	Future Directions to Limit the Transmission of Hepatitis C amongst Injecting Drug Users	337
---	---	-----

10.1.4	Need for Research	339
--------	-------------------	-----

10.1.5	Conclusion	340
--------	------------	-----

<b>10.2</b>	<b>Preventing the Transmission of Hepatitis C in Prisons</b>	<b>341</b>
•	Harm Minimisation Strategies within the Corrections System	342
10.2.1	Preventative Strategies Currently in Place	343
•	Education and Information	344
•	Methadone Maintenance Program	346
•	Safe Tattooing Project	350
•	Availability of Bleach	352
•	Availability of Toothbrushes and Razors	353
•	Diversory Sentencing Practices	355
•	Limit Supply of Drugs Entering Correctional Centres	359
•	Hepatitis B Vaccination Program	361
10.2.2	Hepatitis C Prevention Measures Impacting Upon All Inmates	366
•	Barbers' Shears	366
•	Contact with Blood	366
10.2.3	Hepatitis C Prevention Measures Targeting Injecting Drug Users within the Corrections System	367
•	Education Directed to Injecting Drug Users	367
•	Provision of Sterile Needles and Syringes	368
•	Safe Injecting Rooms	374
•	Availability of Drug Withdrawal Programs	378
•	Abolition of Penalties Associated with Cannabis Use	378
10.2.4	Funding of Hepatitis C Programs	379
10.2.5	Conclusion	381
<b>10.3</b>	<b>Preventing the Transmission of Hepatitis C in the Health Care Setting</b>	<b>381</b>
10.3.1	Preventative Strategies Currently in Place	382
•	Universal Precautions	382
•	Hepatitis B Vaccination Program	383
•	Needlestick Injury Hotline	385
•	Australian Reference Centre for Hepatitis C Information	385
•	Awareness of HCV Status	385
•	Professional Education	386
10.3.2	Proposed Preventative Strategies	387
•	Introduction of National Infection Control Standards	387
•	Awareness of Patient HCV Status	388
•	The Obligations of Hepatitis C Infected Health Care Workers: NSW Health Policy	388
•	Quality Assurance for Endoscopic Units	392
<b>10.4</b>	<b>Preventing the Transmission of Hepatitis C amongst Blood Recipients</b>	<b>393</b>
•	Identification and Exclusion of "at risk" Blood Donors	393

• Serological Testing for HCV Antibodies .....	394
<b>10.5 Preventing the Transmission of Hepatitis C in the Skin</b>	
<b>Penetration Industry</b> .....	<b>395</b>
<b>10.6 Educating and Informing the General Public on Hepatitis C</b> .....	<b>396</b>
• Anticipated Outcomes of a National Community Based Education Campaign .....	398
10.6.1 Research .....	400
<b>10.7 Conclusion</b> .....	<b>401</b>
 <b>CHAPTER ELEVEN:</b>	
<b>CONCLUSION</b> .....	<b>403</b>
<b>11.1 Advocating for those with Hepatitis C</b> .....	<b>406</b>
 <b>Bibliography</b> .....	 <b>411</b>
 <b>Appendix One</b>	
Submissions Received	
 <b>Appendix Two</b>	
Witnesses at Hearings	
 <b>Appendix Three</b>	
Government Response to NSW Hepatitis C Taskforce Report	
 <b>Appendix Four</b>	
Interferon Criteria Comparisons	
 <b>Appendix Five</b>	
NSW Hepatitis C Demonstration Projects: Aims and Objectives	
 <b>LIST OF FIGURES</b>	
Figure One	Estimated Number of People Living with Cirrhosis due to HCV Infection, 1980 - 2010 .....
	42
Figure Two	Estimated Incidence of Hepatocellular Carcinoma due to HCV Infection, 1980 - 2010 .....
	43

Figure Three	Area Health Service Population (%) and HCV Antibody Positive Notifications (%), 1991 - 1997 . . . . .	50
Figure Four	Hepatitis C Standardised Notification Rates per 100,000. Northern Rivers and other NSW Residents, 1992 - 1997 . . . . .	52
Figure Five	Hepatitis C Council of NSW Information and Support Line, 1996 - 1997 . . . . .	280
Figure Six	Applications and Acceptances to Corrections Health Service Methadone Program, 1994/95 - 1995/96 . . . . .	348

**LIST OF TABLES**

Table One	Potential Hepatitic C Transmission Exposure . . . . .	22
Table Two	Possible Factors in Promoting Progression of HCV-related Chronic Liver Disease . . . . .	24
Table Three	Summary of the Various Types of Hepatitis . . . . .	28
Table Four	Summary of HIV and HCV . . . . .	33
Table Five	Hepatitis C Notifications in Australia, 1993 - 1996 . . . . .	47
Table Six	HCV Notifications According to NSW Area Health Services . . . . .	49
Table Seven	Percentage of Injecting Drug Users Seropositive for HCV, by Age, Sex, Age at Interview and Duration of Injecting . . . . .	58
Table Eight	Prevalence of Hepatitis C in a Cohort of Victorian Injecting Drug Users, 1990 - 1995 . . . . .	60
Table Nine	HCV Seroprevalence Among People Attending Needle and Syringe Programs, 1995 and 1996 . . . . .	61
Table Ten	Biennial Incidence of Hepatitis C in a Cohort of Victorian Injecting Drug Users, 1990 - 1995 . . . . .	63
Table Eleven	Risk Factors for Hepatitis C Virus Seroconversion	



	among Injecting Drug Users . . . . .	64
Table Twelve	Hepatitis C in Prison Entrants According to Injecting Status, Victoria, Oct 1991 - Sept 1992 . . . . .	77
Table Thirteen	Incidence of Hepatitis C Amongst Injecting Drug Users and Non-Injecting Drug Users, Victoria, Oct 1991 - Sept 1992 . . . . .	78
Table Fourteen	Location of Tattooing . . . . .	80
Table Fifteen	Residential Location of People with Transfusion Transmitted Hepatitis C . . . . .	83
Table Sixteen	Hepatitis C Status of Patients on Modes of Dialysis in NSW, March 1997 . . . . .	88
Table Seventeen	Hepatitis C Status of Australian Dialysis and Transplant Patients, March 1997 . . . . .	88
Table Eighteen	Impact of HCV on Personal Circumstances . . . . .	106
Table Nineteen	Current NSW Health Hepatitis C Expenditure . . . . .	144
Table Twenty	AIDS Program Funded Health Services with Partial HCV Workload . . . . .	144
Table Twenty-One	Tests Available for Diagnosing and Assessing HCV Infection . . . . .	158
Table Twenty-Two	Diagnostic Evaluation of Hepatitis C . . . . .	162
Table Twenty-Three	Proposed Hepatitis C Testing Protocol . . . . .	163
Table Twenty-Four	Numbers Commencing Interferon Therapy . . . . .	181
Table Twenty-Five	Cost Effectiveness of Interferon Therapy . . . . .	187
Table Twenty-Six	Complementary HCV Treatments . . . . .	194

Table Twenty-Seven	Comparison of the Stringency of Eligibility Criteria for Patient Groups Allowed Access to Interferon under Criteria as Recommended by the National Institutes of Health and NHMRC versus the Section 100 Criteria . . . . .	205
Table Twenty-Eight	Examples of Waiting Lists in NSW . . . . .	233
Table Twenty-Nine	Shared Care Protocol as Proposed by the NHMRC . . . . .	243
Table Thirty	Cost Effectiveness of Needle and Syringe Programs in Australia, 1991 . . . . .	310
Table Thirty-One	Estimated Reduction in the Risk of HCV Transmission to the Surgeon by Adopting Preventative Strategies . . . . .	381

# CHAIR'S FOREWORD

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Hepatitis C is a disease that, it is estimated, impacts upon the lives of up to 200,000 Australians with another 11,000 becoming infected each year. Yet it is a disease that is largely neglected by decision makers, health planners, the media, health care workers and the community in general.

Interest in the disease does, however, seem to be slowly increasing. The Committee noticed this during the course of our Inquiry. A number of significant events took place during the last few months of the Committee's deliberations. These events included: the long awaited publication of two important Australian based papers - Dr Ingrid van Beek's study of the rates of Hepatitis C amongst those attending the Kirketon Road Clinic and Brown and Crofts' analysis of the economic impact of Hepatitis C; the report of the Hepatitis C Virus Projections Working Group containing the most recent projections of incidence and prevalence; a feature on the television program '60 Minutes' on Hepatitis C; the review of the Hepatitis C National Action Plan; and the September issue of *Australian Family Physician* dedicated to Hepatitis C. The Committee hopes that these events, along with the release of this Report, will serve to increase the public profile of Hepatitis C.

The period over which this Inquiry was conducted saw considerable change take place in the Committee's membership. The Hon Ann Symonds, MLC, one of the Committee's original Members and Chair for the past three years, retired and I assumed the Chair. At the same time, the Hon Dorothy Isaksen, MLC was replaced by the Hon Carmel Tebbutt, MLC. The Hon Elisabeth Kirkby, MLC, another longstanding member of this Committee, also retired. Her place was taken by the Hon Dr Arthur Chesterfield-Evans, MLC. I would like to thank all Committee members, both past and present, for the commitment they demonstrated, a commitment to which the unanimity achieved in this report is strong testament. All of the recommendations contained in this Report have our unanimous support. Members have been united in seeking ways to control this epidemic and help to improve the lives of all people affected.

The Committee appreciated the assistance provided by the staff of the Hepatitis C Council of NSW throughout the duration of this Inquiry. The Committee Secretariat staff, in particular, appreciated the enthusiastic cooperation provided by the Council's Executive Officer, Mr Stuart Loveday and Project Officer, Mr Paul Harvey. Stuart and Paul were an invaluable source of the most up-to-date information on all facets of Hepatitis C, and their personal commitment to helping those with Hepatitis C is inspiring.

Most importantly, the Committee wishes to thank the 92 people with Hepatitis C who wrote to us telling what it is like to live with the disease. The Committee also thanks those with Hepatitis C who came and gave oral evidence to the Committee. For some, this task was particularly stressful, yet it provided the Committee with a very clear insight into the everyday realities of living with a chronic and debilitating disease. It was with profound sadness that, towards the end of the Inquiry, the Committee learned of the death of one of its witnesses - Rev Harold Smart. Rev Smart appeared before the Committee to give evidence, despite failing health. The Committee was particularly impressed with the way in which he spoke of the discrimination and stigmatisation he had experienced without a trace of animosity or bitterness. We were touched by his gentle nature and thankful for his contribution.

My thanks are also due to the Committee Secretariat and in particular, Dr Jenny Knight who was responsible for the research and writing of this Report. Dr Knight has presented complex medical and technical information in an extremely readable document. She always displayed compassion and empathy towards the witnesses and others affected by Hepatitis C throughout the course of the Inquiry.

I would also like to thank the Secretariat's Committee Officer, Ms Heather Crichton, for managing the administrative aspects of the Inquiry including processing submissions, arranging hearings and visits and assisting in preparing the final report for printing. As always, Ms Crichton's organisational skills ensured the Inquiry ran smoothly. Ms Beverly Duffy and Ms Julie Langsworth, Senior Project Officers, provided invaluable editorial assistance.

In addition, I would like to thank Ms Gro Frølund and Ms Alison Sherman, two student volunteers who were with the Committee Secretariat during the course of this Inquiry. Ms Frølund undertook a detailed analysis of the written submissions and prepared background notes on the social impact of Hepatitis C. Ms Sherman did a content analysis of the submissions and prepared an overview. The work undertaken by both these students has been of great assistance to the Committee and I thank them for the time they so freely gave.

I commend this report to the Government.

**JAN BURNSWOODS, MLC**

CHAIR

# HEPATITIS C - AT A GLANCE

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<b>Clinical Features</b>	Fatigue, nausea, jaundice, abdominal pain, loss of appetite, and vomiting.
<b>Etiological Agent</b>	Hepatitis C Virus (HCV).
<b>Sequelae</b>	40% of those infected will develop some liver damage. Over a 20 year period 20% will develop cirrhosis. After a further five to ten years, 10% will develop liver cancer or liver failure and require a transplant.
<b>Incidence</b>	8,000 - 11,000 new cases per year.
<b>Transmission</b>	Primarily blood borne Vertical and intrafamilial to a limited extent.
<b>Risk groups</b>	Injecting drug users Prisoners Health care workers Recipients of infected blood/blood products (prior to 1990) Household contacts of infected persons Recipients of tattoos and body piercing.
<b>Trends</b>	Transfusion-associated cases due to infected blood have virtually been eliminated. Most new infections occur amongst injecting drug users. Inmates in correctional centres are a particular 'at risk' group.
<b>Prevention</b>	Harm minimisation strategies Programs to encourage high-risk behaviour modification Screening of blood/organ/tissue donors.

# GLOSSARY

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<b>Aetiology</b>	The cause of the disease
<b>Acute Hepatitis C</b>	A clinical illness consistent with acute Hepatitis C virus infection together with serological evidence of recent exposure
<b>AHMAC</b>	Australian Health Ministers Advisory Council
<b>ALT levels</b>	Alanine Aminotransferase levels in the serum. An indicator of liver function
<b>ANCARD</b>	Australian National Council on AIDS and Related Diseases
<b>Antibody</b>	An immunoglobulin molecule that interacts only with the antigen that induced its synthesis
<b>Anti-HCV+</b>	A sample which is reactive to HCV-Ag in two different licensed enzyme immunoassays
<b>Antigen</b>	Any substance which is capable, under appropriate conditions, of inducing a specific immune response and of reacting with the products of that response
<b>b-DNA</b>	Branched-chain DNA amplification assay: a highly sensitive test to detect viral DNA or CDNA in blood
<b>Chronic Hepatitis C</b>	Patients who have been anti-HCV positive for six months or longer often, but not necessarily, with an accompanying elevation of ALT with or without histological evidence of chronic hepatitis
<b>Cirrhosis</b>	A chronic disease of the liver characterised by nodular regeneration of liver cells and diffuse fibrosis
<b>Decompensated Cirrhosis</b>	Patients with compromised liver function which any additional treatment may further aggravate the condition of the liver

<b>EIA</b>	Enzyme immunoassays: tests used to detect antibody to HCV proteins and used to diagnose HCV infection
<b>Epidemiology</b>	The study of the relationships of various factors determining the frequency and distribution of diseases
<b>Fibrosis</b>	Development of fibrous tissue in an organ
<b>Genotype</b>	The genetic constitution of an organism, as opposed to the phenotype or external appearance of the organism, or the type species of a genus
<b>Haemodialysis</b>	Removal of substances from the blood by virtue of the difference in the rates of their diffusion through a semipermeable membrane
<b>HAV</b>	Hepatitis A virus
<b>HBV</b>	Hepatitis B virus
<b>HCV</b>	Hepatitis C virus
<b>Hepatitis C carrier</b>	A person with HCV viraemia persisting for six months or longer
<b>Horizontal Transmission</b>	The spread of an infectious agent from one individual to another, usually through contact with bodily fluids or excreta
<b>Incidence</b>	The number of new cases of a specific disease in a defined population within a specified period of time
<b>Interferon</b>	A drug approved for the treatment of certain viral infections, including Hepatitis C
<b>NHMRC</b>	National Health and Medical Research Council
<b>Needlestick Injury</b>	Injury occurring accidentally due to needle prick from a syringe containing blood of a person infected with hepatitis or other blood borne disease
<b>Non responders</b>	Patients, who after 12 weeks of interferon therapy, fail to have normalised ALTs
<b>NUAA</b>	NSW Users and AIDS Association

<b>Parenteral</b>	Transmission of a disease not through the alimentary canal, eg. by subcutaneous, intramuscular, intrasternal or intravenous injection
<b>PCR</b>	Polymerase Chain Reaction: a test to detect genetic material (DNA or RNA) in serum or tissues - used here to detect HCV-RNA
<b>Prevalence</b>	The number of cases of a disease in a given population at one point in time
<b>Relapsers</b>	Patients who, after having responded to interferon treatment, subsequently have a recurrence of the disease
<b>Ribavirin</b>	A compound with similar chemical structure to the nucleoside, used in combination with interferon for the treatment of Hepatitis C
<b>S100</b>	Section 100: a particular Pharmaceutical Benefits Scheme listing of certain restricted drugs. The Scheme also establishes the criteria under which patients qualify for interferon treatment
<b>Seroconversion</b>	The production in a host of specific antibodies as a result of infection or immunisation
<b>Serotype</b>	A term used to classify HCV according to the serological response to defined antigenic regions of the virus antigens
<b>Sustained Response</b>	Patients who maintain normal ALT levels and are anti-HCV negative following treatment
<b>Vertical Transmission</b>	Transmission from one generation to another
<b>Viraemia</b>	Presence of virus or viruses in the bloodstream
<b>Viral Load</b>	The level of circulating HCV RNA in a patient's plasma or serum



# KEY CONCLUSIONS

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- It is imperative that **policies and strategic plans are developed** to direct all facets of Hepatitis C including treatment, management and prevention. This commitment to sound Hepatitis C policies must be evident in upgrading the current Hepatitis Advisory Committee to a Ministerial Advisory Committee on Hepatitis C; designing, developing and implementing a NSW Hepatitis C Policy Statement and a NSW Hepatitis C Strategic Plan; providing adequate and ongoing dedicated funding for the implementation of the Policy Statement and Strategic Plan and appointing Area Hepatitis C Managers to the five Area Health Services with exceptionally high levels of Hepatitis C notifications;
- Strategies to **prevent the transmission of Hepatitis C** must be broad and multi-faceted. The Committee fully supports the concept of harm minimisation and considers it to be the most effective underlying principle for strategies to prevent the transmission of Hepatitis C amongst injecting drug users. It is the basis upon which the Committee framed all recommendations directed at injecting drug users (both in the general community and the state's corrections system);
- The Government must recognise that those in the **state's correctional system face an unacceptably high risk of contracting Hepatitis C** and, on release, these people pose a serious danger of dispersing the virus to the wider community. These circumstances warrant radical policies to reduce inmates' exposure to Hepatitis C. The Committee proposes a broad range of prevention strategies; the introduction of a Best Practice Model of treating Hepatitis C amongst inmates and the implementation of a strategic plan to manage Hepatitis C in the corrections system;
- There is an urgent need for **further research** to be undertaken in a number of areas, including: ascertaining the incidence and prevalence of Hepatitis C in the general community as well as in specific population groups such as injecting drug users and prisoners; developing an empirical understanding of the personal, social and economic impact of Hepatitis C; research into the causes of Hepatitis C-related discrimination; clinical studies to identify and understand new treatments for Hepatitis C and the impact upon patients (particularly female

patients) of these new, and existing, treatments; an understanding of the interaction between methadone and interferon and the impact of methadone on pregnancy; research into a range of injecting drug related issues; and studies into the effectiveness of complementary therapies to treat the symptoms of Hepatitis C;

- There appears to be **limited understanding in the community** about Hepatitis C, in particular, about the way in which it is transmitted. Many assume it has the same transmission routes as other blood borne viruses such as HIV/AIDS. Health care workers, including medical specialists, often have a poor understanding of the disease. This lack of understanding manifests itself in a number of ways including discrimination and stigmatisation towards those with Hepatitis C, frustration by those with the disease as they struggle to learn about the disease and sort through conflicting information, and a lack of compassion and tolerance in the general community. To redress this situation, Committee Members have called for the introduction of a number of strategies including education campaigns targeting all those working in the health care sector and public service, the production of an information brochure informing those with Hepatitis C of their legal rights and action they can take to address discrimination, support for the National Hepatitis C Education Program for General Practitioners which seeks to inform and educate general practitioners, and a **national community education Hepatitis C campaign**.

# EXECUTIVE SUMMARY

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Every hour of every day one person in Australia contracts the Hepatitis C virus. While some of these people will shake off the virus, over eighty per cent will go on to live with the disease and its chronic, debilitating effects. Some will require liver transplants, others will die of liver cancer.

The backgrounds of those with the virus are eclectic: current injecting drug users and past injecting drug users now far removed from the practices of their adolescence; infants and children who were infected at birth; prisoners; casualties of the health care system who received infected blood including those as young as eight years and as old as 80 years of age; and health care workers who became infected through their work.

In May 1997 the Legislative Council's Standing Committee on Social Issues was asked to inquire into Hepatitis C (HCV) in New South Wales. This is the first time in Australia that a Parliamentary Committee has been asked to examine this disease and its implications which impact upon such a significant proportion of the community. The Committee was asked to comment on the social and economic impact of the disease; the extent and epidemiology of the virus; the adequacy of policies relating to diagnosis, treatment and prevention; and specific 'at risk' groups including health care workers.

During the course of the Inquiry, the Committee took evidence from 69 witnesses, including some of the nation's most eminent Hepatitis C specialists, in addition to experts in drug and alcohol, epidemiology, virology and public health. Evidence was also taken from agencies providing a range of services to those with Hepatitis C along with people who had the disease. Some of the most poignant and moving evidence came from those with HCV who recounted their first hand experience of dealing with Hepatitis C: the side effects of either the disease itself or the one available drug therapy; the difficulties in accessing information and understanding general practitioners; the overwhelming sense of helplessness as health deteriorates.

Submissions were received from 123 individuals and relevant agencies. A very wide range of people with Hepatitis C made submissions including injecting drug users, prisoners, and those who had contracted Hepatitis C through infected blood or blood products.

An aetiological and epidemiological context for the Report is provided in Chapters Two and Three, which identify and discuss the various features of the Hepatitis C virus along with a thorough analysis of the virus' incidence and prevalence in Australia and, where possible, New South Wales. Evidence received highlighted difficulties in ascertaining, with any degree of accuracy, current rates of Hepatitis C. Recommendations call for regular and ongoing prevalence and incidence studies to

be conducted at both the state and national level and amongst the general community as well injecting drug users and inmates of the state's correctional system.

The Committee was specifically asked to examine the social impact of Hepatitis C. Members came to appreciate that the disease impacts upon the lives of people in a myriad of ways. The debilitating fatigue, for example, limits relationships, work and interactions with children - even simple household tasks. Many recounted to Members the fear they have of neighbours, work colleagues, even family members finding out their Hepatitis C status and the prejudice and stigma that would come with that knowledge. Stories were shared of blatant discrimination and misunderstanding from community members, even health care workers, who fear a disease they know so little about.

The economic impact of the disease is also examined. Current research suggests that every one thousand new injecting drug users infected with Hepatitis C will generate, over their lifespan, \$14.32 million worth of direct medical care costs to the Commonwealth. This potential bill does not take into account other economic costs such as lost production (paid and unpaid time off work), the cost of support services such as respite care and Meals on Wheels or the personal cost, in terms of pain and fatigue, to those with the disease.

Despite the current Hepatitis C epidemic, there are no policies at the state level giving overall direction to the control, treatment, management and prevention of this disease. To overcome the current inadequate situation, the Committee has forwarded a number of recommendations including the upgrade of the Hepatitis Advisory Committee to a Ministerial Advisory Committee on Hepatitis C; the design, development and implementation of a NSW Hepatitis C Policy Statement and a NSW Hepatitis C Strategic Plan; adequate and ongoing dedicated funding for the implementation of the Policy Statement and Strategic Plan and the appointment of Area Hepatitis C Managers to the five Area Health Services with exceptionally high levels of HCV notifications.

An important part of managing Hepatitis C is the provision of specialised diagnostic tests. Chapter Six reviews the current diagnostic tests available and the shortcomings in the delivery of diagnostic services. Many of those writing to the Committee spoke of the shock and distress they experienced when they first learned of their Hepatitis C status. The Committee considers it essential that pre- and post-test counselling be provided as a routine practice for all those undergoing HCV testing.

The current treatment regime for Hepatitis C is the drug interferon which is freely available for a twelve month period only to those who meet the strict S100 criteria: policies determine who will receive interferon, where interferon can be administered and how much interferon can be given. The Committee considered these policies, and others that limit pre-treatment assessment, restrict ongoing treatment assessment and monitoring and the availability of PCR testing for HCV+ women considering pregnancy. Recommendations addressing each of these issues are forwarded. The Report also identifies inadequacies in the current treatment regime and methods of delivering health care and examines models of best practice to address these shortcomings. The

Committee specifically recommends that the Minister for Health develop a model of best practice for the delivery of health services to those with Hepatitis C. This model is to be flexible and provide services in a range of formats appropriate to the diverse needs (including geographical location) of those with Hepatitis C.

The report identifies a number of difficulties currently being experienced in treating and managing Hepatitis C positive inmates of the state's correctional system. The Committee calls for the development of a best practice model for the delivery of health care in prisons and stipulates that the model address identified shortcomings of the current system including the limited number of available health care professionals, the limited number of inmates accessing interferon and identified difficulties currently associated with administering interferon to inmates. The Committee also recommends the development, implementation and funding of a strategic plan for the management of Hepatitis C in the state's correctional system.

Many of those with Hepatitis C need, or would appreciate, various forms of support ranging from information and advice to help with household tasks or child care. However a common theme running through the submissions and evidence from those with Hepatitis C was the lack of support available and difficulties accessing what limited support is available. A series of recommendations are forwarded to address the current inadequacies. These include enhanced funding to the Hepatitis C Council's Telephone Information and Support Service to enable it to increase its hours of operation and the trial of an Interagency Hepatitis C Support Project made up of the Departments of Health, Community Service, Housing and Transport and local government representatives. The aim of the Project would be to ensure government services are readily available and accessible to those in need.

The chapter addressing issues to limit the transmission of Hepatitis C is approximately 100 pages in length, which is indicative of the importance Committee Members attach to prevention. The emphasis of the chapter is on the two population groups considered to be at greatest risk of contracting Hepatitis C: injecting drug users and inmates of the state's correctional system.

The Committee considers it essential that the Government recognise that the major risk of infection with the Hepatitis C virus is borne by injecting drug users and that effective strategies to minimise this practice are essential to prevent transmission. The Committee wishes to see the Government review its harm minimisation strategies in the light of the known epidemiology of Hepatitis C. Proposed strategies to limit the spread of Hepatitis C amongst injecting drug users include an expansion of strategies already in place such as peer-based education, the needle and syringe program and the methadone maintenance therapy program. In addition new strategies targeting those who inject and measures to prevent or delay initial injecting should be urgently pursued.

The Committee also considers it imperative that the Government recognise that the prison population faces an unacceptably high risk of contracting Hepatitis C and, on release, these people pose a serious danger of transmitting the virus to the wider community. The Committee feels that these circumstances warrant radical policies to

reduce inmates' exposure to Hepatitis C in correction establishments. Current preventative strategies are reviewed and recommendations to strengthen and expand them have been proposed.

Considerable support was given by witnesses and those making submissions to a national community education Hepatitis C campaign. It was anticipated that such a campaign would raise the awareness of the disease amongst the general community, which would, in turn, lessen discrimination and stigmatisation and raise tolerance and compassion towards those with the virus. Such a campaign would also alert those at risk of contracting Hepatitis C and those who may have engaged in 'at risk' behaviours in the past.

Throughout the Report a number of recommendations call for research to be conducted. While the Committee appreciates that some research is underway, there are a number of specific areas that require further research such as ascertaining the incidence and prevalence of Hepatitis C in the general community as well as specific population groups such as injecting drug users and prisoners; an empirical understanding of the personal, social and economic impact of Hepatitis C; and research into the effectiveness of complementary therapies to treat the symptoms of Hepatitis C.

Finally, the Committee recognised that, for a number of reasons, there is no single body that advocates for those with Hepatitis C. In response, and given the growing seriousness of the Hepatitis C epidemic facing New South Wales, the Committee has recommended the formation of a Hepatitis C NSW Parliamentary Liaison Group.

Throughout the course of this Inquiry, Committee Members have been overwhelmed with the enormity of the Hepatitis C issue. Not only is the disease one of epidemic proportions, but it is one that, given its chronic nature, touches every facet of the lives of those with the disease and the lives of their immediate families.

Committee Members have resolved to address current inadequacies and have unanimously proposed a framework for the state to respond appropriately and adequately to this disease which, to date, has been neglected. The Committee now seeks a similar resolve from the government: a resolve backed by political will and motivated by compassion. Hepatitis C is an epidemic that can no longer be neglected.

# SUMMARY OF RECOMMENDATIONS

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**RECOMMENDATION 1:**

That the Minister for Health urge his Federal counterpart to commission population **prevalence** studies of Hepatitis C at the national level to determine the prevalence of Hepatitis C in the general Australian community. The Committee further recommends that such studies be conducted on a regular and ongoing basis.

**RECOMMENDATION 2:**

That the Minister for Health commission population **prevalence** studies of Hepatitis C at state level to determine the prevalence of Hepatitis C in New South Wales. The Committee further recommends that such studies be conducted on a regular and ongoing basis.

**RECOMMENDATION 3:**

That the Minister for Health urge his Federal counterpart to commission population **incidence** studies of Hepatitis C at the national level to determine the incidence of Hepatitis C in the general Australian community. The Committee further recommends that such studies be conducted on a regular and ongoing basis.

**RECOMMENDATION 4:**

That the Minister for Health commission population **incidence** studies of Hepatitis C at state level to determine the incidence of Hepatitis C in New South Wales. The Committee further recommends that such studies be conducted on a regular and ongoing basis.

**RECOMMENDATION 5:**

That the Minister for Health urge his federal counterpart to establish systems to monitor Hepatitis C related cirrhosis and hepatocellular carcinoma at the national level.

**RECOMMENDATION 6:**

That NSW Health establish systems to monitor Hepatitis C related cirrhosis and hepatocellular carcinoma in New South Wales.

**RECOMMENDATION 7:**

That at the next Australian Health Ministers' Council the Minister for Health urge his federal, state and territory counterparts to establish clinical based morbidity registers to monitor Hepatitis C deaths.

**RECOMMENDATION 8:**

That NSW Health establish a clinically based morbidity register to monitor Hepatitis C related deaths in New South Wales.

**RECOMMENDATION 9:**

That the Minister for Health urge his Federal counterpart to institute standardised procedures for the notification of Hepatitis C across all states and territories of Australia.

**RECOMMENDATION 10:**

That the Minister for Health commission a prospective, longitudinal cohort study to ascertain the **prevalence** of Hepatitis C amongst injecting drug users (including young recently initiated injecting drug users and clients of the needle and syringe program) in metropolitan and rural New South Wales. This study is to be in addition to the general population prevalence studies proposed in Recommendation 2.

**RECOMMENDATION 11:**

That the Minister for Health commission a prospective, longitudinal cohort study to ascertain the **incidence** of Hepatitis C amongst injecting drug users (including young recently initiated injecting drug users and clients of the needle and syringe program) in metropolitan and rural New South Wales. This study is to be in addition to the general population incidence studies proposed in Recommendations 4.



**RECOMMENDATION 12:**

That the prospective, longitudinal cohort study to ascertain the incidence and prevalence of Hepatitis C amongst injecting drug users proposed in Recommendations 10 and 11 be based upon the Victorian Injecting Drug Study and, like the Victorian model, be conducted by an independent agency.

**RECOMMENDATION 13:**

That the Minister for Corrective Services and the Minister for Health ensure the prevalence of Hepatitis C in the state's corrections system is ascertained through ongoing monitoring and research.

**RECOMMENDATION 14:**

That the Ministers for Health and Corrective Services ensure adequate funding is allocated to ongoing monitoring and research of the prevalence of Hepatitis C in the state's corrections system.

**RECOMMENDATION 15:**

That the testing proposed in Recommendation 13 incorporate PCR testing to ascertain the viraemic status of HCV+ prison inmates.

**RECOMMENDATION 16:**

That the Minister for Corrective Services, in conjunction with the Minister for Health, commission an independent study of the incidence and modes of transmission of Hepatitis C in the state's corrections system. This study is to be in addition to the population incidence study proposed in Recommendation 4.

**RECOMMENDATION 17:**

That the Ministers for Health and Corrective Services ensure adequate funding is allocated to ongoing monitoring and research of the incidence and modes of transmission of Hepatitis C in the state's corrections system.

**RECOMMENDATION 18:**

That the independent study of Hepatitis C incidence proposed in Recommendation 16 be conducted on a regular basis to ensure information on the incidence and modes of transmission of Hepatitis C in the state's corrections system is gathered over time.

**RECOMMENDATION 19:**

That NSW Health design and implement an awareness campaign for all those working in the health care system addressing practices, values and attitudes that discriminate against those with Hepatitis C accessing the health care system.

**RECOMMENDATION 20:**

That the Minister for Health meet with representatives of the various professional colleges (including the Royal College of Surgeons, Royal College of General Practitioners, and Royal College of Nursing) and unions and urge them to support the awareness campaign addressing Hepatitis C related discrimination in the health care system proposed in Recommendation 19.

**RECOMMENDATION 21:**

That the Attorney-General instruct the Anti-Discrimination Board to conduct an inquiry into discrimination and Hepatitis C in New South Wales. The Committee further recommends that the resultant report of this inquiry be distributed widely to relevant employer and employee organisations, trade unions, education institutions, hospitals and relevant community organisations (such as the Hepatitis C Council of NSW) across the state.

**RECOMMENDATION 22:**

That the Premier direct an education campaign be designed and implemented across all sectors of the public service addressing practices, values and attitudes that discriminate against those with Hepatitis C and ensuring that those working for the government are aware of the illegality of discriminating against those with Hepatitis C.

**RECOMMENDATION 23:**

That the Anti-Discrimination Board of New South Wales design an information brochure informing those with Hepatitis C of their legal rights and action they can take to address discrimination. The Committee further recommends that the Hepatitis C Council of NSW be given responsibility (and adequate funding) to distribute this brochure.

**RECOMMENDATION 24:**

That the Attorney General provide adequate funding to the Anti-Discrimination Board of New South Wales for the design and development of the information brochure proposed in Recommendation 23.

**RECOMMENDATION 25:**

That the Minister for Health direct research be undertaken into the personal, social and economic costs of Hepatitis C infection to individuals, the state's health care system and to society.

**RECOMMENDATION 26:**

That the Attorney General request the NSW Anti-Discrimination Board conduct (or commission) social research into the causes of Hepatitis C-related discrimination.

The Committee further recommends that the findings of the proposed research be used in formulating programs to combat this form of discrimination including those programs proposed in Recommendations 19, 22 and 129.

**RECOMMENDATION 27:**

That the Minister for Health upgrade the Hepatitis Advisory Committee to become the Ministerial Advisory Committee on Hepatitis C. The Committee further recommends that the Terms of Reference of the Ministerial Advisory Committee on Hepatitis C include:

1. to advise the Minister on clinical, education/prevention, health promotion and surveillance policy and strategic directions for the prevention, care and treatment of Hepatitis C;
2. to participate in the design and development of the statewide policy statements and strategic plans for Hepatitis C;
3. to liaise with other Committees and professional groups of relevance to Hepatitis C; and
4. to promote research and training in Hepatitis C.

**RECOMMENDATION 28:**

That the Minister for Health direct NSW Health to design and develop a NSW Hepatitis C Policy Statement to give overall direction to the control, treatment, management and prevention of Hepatitis C and the care and support of those with the disease.

The Committee further recommends that the proposed NSW Hepatitis C Policy Statement include, as a minimum, a broad vision statement of the direction to be taken in Hepatitis C support, control, treatment, management and prevention, along with supporting guiding principles and policy aims.

The Committee further recommends that NSW Health undertake an evaluation of the NSW Hepatitis C Policy Statement in January 2001 to assist in determining future responses and directions.

**RECOMMENDATION 29:**

That the NSW Hepatitis C Policy Statement proposed in Recommendation 28 be the basis for all future planning and funding for Hepatitis C in the state.

**RECOMMENDATION 30:**

That the Minister for Health ensure adequate consultation with the major stakeholders during the process of designing and developing the NSW Hepatitis C Policy Statement proposed in Recommendation 28. Those consulted are to include, yet not be limited to, representatives of the Hepatitis C Council and relevant community groups such as NUAA, liver specialists, public health experts, epidemiologists, clinical nurse consultants.

The Committee further recommends that the Ministerial Advisory Committee on Hepatitis C be actively involved in the design and development of the NSW Hepatitis C Policy Statement proposed in Recommendation 28.

**RECOMMENDATION 31:**

That the Minister for Health direct NSW Health to develop a NSW Hepatitis C Strategic Plan within the context of the NSW Hepatitis C Policy Statement proposed in Recommendation 28 and that the Strategic Plan clearly articulate how, when and where the state will address all facets of Hepatitis C control, treatment, management and prevention along with care and support for those with the disease.

The Committee further recommends that NSW Health undertake an evaluation of the NSW Hepatitis C Strategic Plan in January 2001 to assist in determining future responses and programs.

**RECOMMENDATION 32:**

That the NSW Hepatitis C Strategic Plan proposed in Recommendation 31 identify goals, objectives and key strategies along with detailed implementation plans for each objective.

**RECOMMENDATION 33:**

That NSW Health ensure the NSW Hepatitis C Policy Statement (proposed in Recommendation 28) and NSW Hepatitis C Strategic Plan (proposed in Recommendation 31) are placed on the Department's website.

**RECOMMENDATION 34:**

That the Minister for Health ensure adequate and ongoing dedicated funding is provided for the full implementation of the NSW Hepatitis C Policy Statement proposed in Recommendation 28 and the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

**RECOMMENDATION 35:**

That the Minister for Health urge his federal counterpart to provide funding allocations which reflect more accurately the rate of Hepatitis C in New South Wales and the state's need for support services and prevention strategies.

**RECOMMENDATION 36:**

That the Minister for Health ensure dedicated, adequate and appropriately graded full time and permanent staff are assigned within the AIDS and Infectious Diseases Branch of NSW Health to oversee the implementation of the NSW Hepatitis C Policy Statement proposed in Recommendation 28 and the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

**RECOMMENDATION 37:**

That the Minister for Health direct South Eastern Sydney, South Western Sydney, Western Sydney, Northern Sydney and Northern Rivers Area Health Services develop and implement Regional Hepatitis C Strategic Plans in line with the NSW Hepatitis C Policy Statement (as proposed in Recommendation 28) and the NSW Hepatitis C Strategic Plan (as proposed in Recommendation 31). This measure should be achieved through contract performance arrangements between NSW Health and the Area Health Services.

**RECOMMENDATION 38:**

That the Minister for Health ensure adequate and ongoing dedicated funding is provided for the full implementation of the regional Hepatitis C Strategic Plans proposed in Recommendation 37.

**RECOMMENDATION 39:**

That the Minister for Health review all Area Health Services to determine the needs of each Area Health Services for Area Hepatitis C Managers.

**RECOMMENDATION 40:**

That the Minister for Health instruct that, as a matter of priority, the position of dedicated Area Hepatitis C Manager be established and filled in the following Area Health Services: South Eastern Sydney; Western Sydney; South Western Sydney; Central Sydney and Northern Rivers. The Committee further recommends that the position of dedicated Area Hepatitis C Manager be in addition to existing positions of Area HIV/AIDS Managers which may currently exist in the identified Area Health Services.

**RECOMMENDATION 41:**

That the Minister for Health ensure dedicated funding is allocated to the South Eastern Sydney, Western Sydney, South Western Sydney, Central Sydney and Northern Rivers Area Health Services for the establishment of Area Hepatitis C Manager positions.

**RECOMMENDATION 42:**

That the Minister for Health instruct that the positions of Area Hepatitis C Manager in the South Eastern Sydney, Western Sydney, South Western Sydney, Central Sydney and Northern Rivers Area Health Services be incorporated in the review of Hepatitis C staffing needs proposed in Recommendation 39. The Committee further recommends that, following this review, and where necessary additional staff dedicated to Hepatitis C management at the local Area Health Service level be appointed.

**RECOMMENDATION 43:**

That the Minister for Health call tenders for the establishment of three major Hepatitis C reference laboratories in NSW. Selection of the laboratories should be based on the expertise and experience of the laboratories, the ability to interpret tests and develop new tests, and their capacity to participate in state-wide and national quality assurance programs. The reference laboratories should be able to conduct validation testing for private laboratories for a fee.

**RECOMMENDATION 44:**

That the Minister for Health ensure adequate funding is available to the Hepatitis C reference laboratories proposed in Recommendation 43 and that the funding allocation to the reference laboratories be made from NSW Health funds rather than the local area health services.

**RECOMMENDATION 45:**

That NSW Health recognise the provision of pre- and post-test information and counselling by health care professionals provides best practice patient management in relation to testing for Hepatitis C. The Committee further recommends that the Ministerial Advisory Committee on Hepatitis C proposed in Recommendation 27 develop a set of policy guidelines for pre-and post-testing for Hepatitis C for health practitioners in NSW and that these guidelines ensure pre- and post test counselling are a routine practice for all people considering HCV testing.

**RECOMMENDATION 46:**

That the Minister for Health urge his federal counterpart to encourage the Pharmaceutical Benefits Advisory Committee to broaden the assessment criteria for interferon drug therapy under the S100 Highly Specialised Drugs Scheme to include:

- patients with minimal ALT elevation or with normal liver function tests and positive hepatitis serology or HCV-RNA testing;
- patients with cirrhosis (dosage - 4.5MU daily);
- relapsers and non-responders; and
- patients with extrahepatic manifestations of Hepatitis C.

The Committee further recommends that the proposed new S100 assessment criteria for interferon be monitored for two years with patient response data continuing to be collected for the National Interferon Database.

**RECOMMENDATION 47:**

That the Minister for Health urge his federal counterpart to ensure funding continues to be provided to maintain operation of the National Interferon Database and that the intellectual property of the Database remain with the government so that optimum treatment regimes can be ascertained.

**RECOMMENDATION 48:**

That the NSW Hepatitis C Policy and the NSW Hepatitis C Strategic Plan (proposed in Recommendations 28 and 31) address the management needs of those who are HCV-positive and ineligible for interferon therapy. Issues to be considered are to include (although not be limited to) (i) information on the natural history of the disease, treatment options, health promotion and cross-infection and re-infection; (ii) counselling needs and psychosocial support of these patients and their families; and (iii) the role of primary health care providers in giving this support.

**RECOMMENDATION 49:**

That the Minister for Health seek the support of his Federal counterpart for a review of the criteria used to establish Interferon Prescribing Centres to enable the expansion of the limited number of hospitals allowed to dispense interferon without compromising clinical standards or cost controls.

**RECOMMENDATION 50:**

That the Minister for Health approach his Federal counterpart and seek his support for PCR testing used to determine genotyping and viral load in the pre-treatment assessment for patients considering interferon (and other drug) therapy to be fully covered either under the Medicare Benefits Schedule or hospital block funding.

**RECOMMENDATION 51:**

That the Minister for Health urge his Federal counterpart to encourage the Pharmaceutical Benefits Advisory Committee to introduce a degree of flexibility into the S100 Highly Specialised Drugs Scheme enabling the interferon dosage schedule to be increased where necessary and appropriate such as in the case of cirrhotic patients.

**RECOMMENDATION 52:**

That the Minister for Health approach his Federal counterpart and seek his support for PCR testing used to monitor interferon (and other drug) therapy and tailor therapy to ensure maximum efficacy of treatment and efficient utilisation of resources to be fully covered either under the Medicare Benefits Schedule or hospital block funding.



**RECOMMENDATION 53:**

That the Minister for Health approach his Federal counterpart and seek his support for PCR testing used to predict the relative risk of vertical transmission during pregnancy to be fully covered either under the Medicare Benefits Schedule or hospital block funding.

**RECOMMENDATION 54:**

That the Minister for Health request his federal counterpart fund and support clinical studies to identify and understand new treatments for Hepatitis C and the impact upon patients (particularly female patients) of these new, and existing, treatments. The Committee further recommends that the state government match federal funding for this research on a dollar for dollar basis.

**RECOMMENDATION 55:**

That the Strategic Plan proposed in Recommendation 31 consider the provision of adequate support mechanisms for people who do not respond to interferon therapy. The Committee further recommends that the Strategic Plan set targets for the establishment of support services in inner city, metropolitan and regional/rural locations.

**RECOMMENDATION 56:**

That NSW Health provide HCV specific training (both initial and ongoing) to existing providers of psychosocial support for people with chronic illness employed within the health care system, such as social workers, counsellors, chaplains, drug and alcohol workers enabling these professionals to provide support to those on interferon therapy.

**RECOMMENDATION 57:**

That the Minister for Health, through the forum of the Australian Health Ministers' Council, urge his federal, state and territory counterparts to recognise Australia's low rate of organ donation and consider innovative and effective ways to increase the donations of organs in general and liver donations specifically.

**RECOMMENDATION 58:**

That the Minister for Health state his government's commitment to providing adequate and appropriate health care - from primary through to tertiary health care - to all those in NSW who are Hepatitis C positive.

**RECOMMENDATION 59:**

That the NSW Hepatitis C Policy Statement proposed in Recommendation 28 clearly enunciates the Minister's commitment to providing adequate and appropriate health care to all those in NSW who are Hepatitis C positive. The Committee further recommends that the NSW Hepatitis C Strategic Plan proposed in Recommendation 31 clearly identifies the way in which the Minister's commitment will be realised along with appropriate time frames and funding allocations.

**RECOMMENDATION 60:**

That the NSW Hepatitis C Strategic Plan be the basis upon which NSW Health allocates funding to treat and manage Hepatitis C.

**RECOMMENDATION 61:**

That NSW Health conduct a comprehensive needs assessment and service planning exercise within six months of this Report being tabled. This exercise is to include the provision of services in all health areas and all public hospitals.

The Committee further recommends that the Department set minimum service levels based on a health outcomes approach.

**RECOMMENDATION 62:**

That NSW Health incorporate the implementation of the results of the needs assessment and the service planning exercise into the Strategic Plan proposed in Recommendation 61.

**RECOMMENDATION 63:**

That the Minister for Health allocate funding for the implementation of the results of the needs assessment and service planning exercise proposed in Recommendation 61.

**RECOMMENDATION 64:**

That the Minister for Health accept the principle of shared care as a viable and practical clinical management tool for Hepatitis C and ensure NSW Health takes all possible measures for shared care of Hepatitis C patients to be introduced into the New South Wales health care system.

**RECOMMENDATION 65:**

That the Minister for Health ensure all measures are taken for the full and unhindered implementation of the National Hepatitis C Education Program for General Practitioners in New South Wales.

**RECOMMENDATION 66:**

That the NSW Hepatitis C Policy Statement (proposed in Recommendation 28) and the NSW Hepatitis C Strategic Plan (proposed in Recommendation 31) address the issue of a Hepatitis C Education Strategy for Health Care Workers. The Education Strategy is to ensure that appropriate material, resources and training are available to health care workers throughout the state, enabling those responsible for delivering health care to access relevant information. Wherever possible, the Committee would like to see the Education Strategy be integrated with other education and training activities and initiatives. The Committee further recommends that the Minister for Health ensure the Hepatitis C Education Strategy for Health Care Workers is adequately funded.

**RECOMMENDATION 67:**

That NSW Health develop a Best Practice Model for the delivery of services to those with Hepatitis C in New South Wales. The Committee stipulates that the best practice model be flexible to provide delivery services in a range of formats appropriate to the diverse needs (including geographical location) of those with Hepatitis C. The Committee further recommends that NSW Health take into account the evaluations of the RACGP's National Hepatitis C Education Program for General Practitioners, the four NSW Health demonstration projects, the HepCare trial and the results of the comprehensive needs assessment and service planning exercise proposed in Recommendation 61 in developing best practice models for the delivery of services to those with Hepatitis C.

**RECOMMENDATION 68:**

That the strategies to be implemented in establishing the model of best practice for the delivery of services to those with Hepatitis C in NSW be incorporated in the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

**RECOMMENDATION 69:**

That the Minister for Health ensure adequate funding is available for the implementation of the model of best practice for the delivery of services to those with Hepatitis C in NSW.

**RECOMMENDATION 70:**

That the Minister for Health urge his federal counterpart to encourage the NHMRC to support and fund research trials of complementary therapies designed to relieve the symptoms of Hepatitis C.

**RECOMMENDATION 71:**

That the Minister for Corrective Services ensure the program offered at the Lifestyle Unit be expanded (in both scope and size) to respond more adequately to the prevalence of Hepatitis C within the corrections system. The Committee further recommends that the program be extended to include female inmates who are Hepatitis C positive.

**RECOMMENDATION 72:**

That the Department of Corrective Services and Corrections Health Service recognise the extraordinarily high rates of Hepatitis C amongst inmates in the state's correctional system and develop a Best Practice Model for the delivery of Hepatitis C health care services to these inmates as a matter of priority. The Committee believes that the Best Practice Model must provide specific care to male and female HCV+ inmates located in both rural and metropolitan correctional centres. The Committee further recommends that the Best Practice Model must overcome shortcomings in the current provision of health care identified in this Inquiry, including the shortage of available health care professionals, the limited number of inmates able to access interferon therapy, and the difficulties currently experienced in administering interferon to inmates.

**RECOMMENDATION 73:**

That the strategies to be implemented in establishing the Best Practice Model for the delivery of health care to those with Hepatitis C in NSW be incorporated in the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

**RECOMMENDATION 74:**

That the Minister for Health and the Minister for Corrective Services ensure funding is available for the implementation of the model of best practice for the delivery of health care to those with Hepatitis C in the state's correctional system.

**RECOMMENDATION 75:**

That the Minister for Health and the Minister for Corrective Services form an Intersectorial Committee made up of representatives from Department of Corrective Services, Corrections Health Service, NSW Health and specialists (both medical practitioners and clinical nurses). This Committee should be required to develop a strategic plan to address issues including, though not be limited to:

- provision of low fat diets to HCV+ inmates;
- availability of light duties for those experiencing Hepatitis C and/or interferon side effects;
- the education of prison officers on Hepatitis C and/or interferon side effects;
- in-service training for public health unit nurses on a range of Hepatitis C related issues including interferon therapy regimes;
- the design of post-release care plans for HCV+ inmates; and
- management difficulties experienced by those inmates on interferon therapy.

**RECOMMENDATION 76:**

That the implementation details of the strategic plan for the management of Hepatitis C in the state's correctional system proposed in Recommendation 75 be incorporated in the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

**RECOMMENDATION 77:**

That the Minister for Health and the Minister for Corrective Services ensure funding is available for the implementation of strategic plan for the management of Hepatitis C in the state's correctional system.

**RECOMMENDATION 78:**

That the Minister for Health and the Minister for Corrective Services take active steps to ensure officers from the Department of Corrective Services and Corrections Health Service/NSW Health (not only at the central agency level, but at the local correctional centre level) collaborate effectively.

**RECOMMENDATION 79:**

That the funding allocation by NSW Health to the Hepatitis C Council of NSW be increased to enable the Telephone Information and Support Service to operate from 9:00am to 6:00pm seven days a week and from 6:00pm to 10:00pm Monday to Friday evenings.

**RECOMMENDATION 80:**

That NSW Health commission an independent review and needs assessment of the services provided by the Hepatitis C Council of NSW, the Transfusion Related AIDS and Infectious Diseases Unit, the Haemophilia Foundation NSW, and New South Wales Users and AIDS Association to determine resource needs (including staffing needs for counselling, support, project and policy work and volunteer management) and demand for services. The Committee further recommends that the proposed review be conducted within six months of the tabling of this Report and that the results are with the Minister for Health no later than December 1999.

**RECOMMENDATION 81:**

That, upon receipt of the review proposed in Recommendation 80, NSW Health ensure sufficient and recurrent funding is made available to implement the recommendations of the review.

**RECOMMENDATION 82:**

That the Area Hepatitis C Managers proposed in Recommendation 40 be responsible for instigating Hepatitis C Support Groups in their local Health Areas and, while not necessarily involved in the day to day operation of the groups, provide expert input and information as required, act as a resource/referral person and ensure necessary resources are available.

**RECOMMENDATION 83:**

That the review proposed in Recommendation 39 take into consideration the need for support groups in each Health Area and the role played by Area Hepatitis C Managers in facilitating these groups.

**RECOMMENDATION 84:**

That, in developing a model of best practice for the delivery of services to those with Hepatitis C (as proposed in Recommendation 67), the accommodation needs of local Hepatitis C support groups be take into account.

**RECOMMENDATION 85:**

That NSW Health maintain a watching brief on the issue of changes to the Disability Support Pension. The Committee further recommends that, should changes be proposed in the future which would restrict those genuinely debilitated by Hepatitis C from accessing the Disability Support Pension, the Minister for Health, through the

forum of the Australian Health Ministers Council, advocate on behalf of those with Hepatitis C.

**RECOMMENDATION 86:**

That NSW Health trial an Interagency Hepatitis C Support Project to ensure government services required by those with Hepatitis C are readily available and accessible. The Committee further recommends that the government agencies involved include the Departments of Health, Community Services, Housing and Transport in addition to local government representation.

**RECOMMENDATION 87:**

That the Interagency Hepatitis C Support Project proposed in Recommendation 86 be trialed for a two year period in three Health Areas: Central Sydney Area Health Service (inner city), South Western Sydney Area Health Service (metropolitan) and Northern Rivers Area Health Service (rural). The Committee further recommends that the Area Hepatitis C Managers for each of these Health Areas proposed in Recommendation 40 act as project coordinator and chair of the Committee.

**RECOMMENDATION 88:**

That the NSW Hepatitis C Policy Statement proposed in Recommendation 28 clearly state the Department's policy to prevent the transmission of Hepatitis C amongst target populations. The Committee further recommends that the NSW Hepatitis C Strategic Plan proposed in Recommendation 31 clearly identify the direction to be taken to prevent the transmission of Hepatitis C amongst target populations. The Plan should identify existing preventative strategies, include a range of new preventative measures that are innovative and effective and be the basis for funding and evaluation.

**RECOMMENDATION 89:**

That the NSW Hepatitis C Policy Statement (proposed in Recommendation 28) clearly identify the Department's policy to prevent the transmission of Hepatitis C in the injecting drug user population. The Committee further recommends that the NSW Strategic Plan (proposed in Recommendation 31) clearly identifies strategies that will be put in place to prevent the transmission of Hepatitis C amongst the state's drug injecting population.

**RECOMMENDATION 90:**

That NSW Health recognise and utilise more fully the role that the Methadone Maintenance Therapy Program plays in minimising the transmission of Hepatitis C amongst injecting drug users. The Committee further recommends that methadone therapy facilities be expanded and made available throughout the state. Resources should be made available to the Methadone Maintenance Therapy Program to provide initial education, counselling and support services for people who are Hepatitis C positive.

**RECOMMENDATION 91:**

That the Minister for Health, through the Australian Health Ministers' Council, urge the National Health and Medical Research Council to commission and fund research into the interaction between methadone and interferon and the impact of methadone on pregnancy.

**RECOMMENDATION 92:**

That, given the high content level of alcohol in methadone and the impact this has upon those on methadone maintenance therapy who are also undergoing interferon therapy, the Minister for Health conduct a rigorous scientific trial of all alternative therapies for this group of people. The Committee further recommends that an independent advisory committee be established to develop the trial protocol, oversee the trial and review the trial's subsequent evaluation.

**RECOMMENDATION 93:**

That the Minister for Police review the instructions concerning police patrols within the proximity of needle and syringe outlets and that the instructions clearly state that:

- i) maximum and effective use of needle and syringe outlets is an effective preventative measure against the transmission of Hepatitis C and other blood borne diseases; and
- ii) clients' access to needle and syringe outlets is to be unhindered and without fear of intimidation or arrest.

**RECOMMENDATION 94:**

That the Minister for Health recognise the role of the Needle and Syringe Program in minimising the transmission of Hepatitis C amongst injecting drug users. The Committee further recommends that the Program be further developed and extended in its reach and range of services so that outlets throughout the state provide:



- education and information (including available treatment options), counselling and support services to people who are Hepatitis C positive;
- increased after-hours service;
- access to sterile water, alcohol swabs and cotton wool filters; and
- for integrated services in conjunction with other community health programs.

**RECOMMENDATION 95:**

That the Minister for Health ensure the Needle and Syringe Program is adequately resourced to take on the additional functions proposed in Recommendation 94.

**RECOMMENDATION 96:**

That NSW Health design strategies targeting those who have just commenced injecting practices to warn them of the inherent dangers of contracting Hepatitis C from unhygienic equipment and to encourage them to utilise fully the services offered by needle and syringe outlets. The Committee further recommends that the Needle and Syringe Program be resourced to implement the proposed strategies.

**RECOMMENDATION 97:**

That NSW Health ensure workers at needle and syringe outlets are adequately skilled and trained to provide HCV specific information.

**RECOMMENDATION 98:**

That NSW Health provide funding for a state-wide peer based education campaign on the importance of blood awareness amongst injecting drug users. The Committee further recommends that representatives from the Hepatitis C community and other appropriate interest groups be involved in the development and implementation of the proposed education strategies to ensure the strategies are practical and effective and appropriate.

**RECOMMENDATION 99:**

That NSW Health and the Department of Education and Training ensure the basic message of all preventative strategies to prevent or delay initial injecting behaviour in adolescents is a very clear one that encourages young people not to take drugs.

**RECOMMENDATION 100:**

That the Minister for Health and the Minister for Education and Training meet and reach an agreement on the role to be played by the Department of Education and Training in providing Hepatitis C education to children and young people in the state's school system. The Committee further recommends that the two Ministers give consideration to the following aims for Hepatitis C education within the school system:

- to prevent infection with HCV by discouraging young people from engaging in risk behaviours; and
- to provide information on harm minimisation for young people who may have already become involved in drug use.

**RECOMMENDATION 101:**

That the Department of Education and Training develop school-based education programs to raise student awareness on issues including:

- the nature of Hepatitis C, including epidemiology, transmission and risk behaviours;
- a range of strategies to assist students to avoid injecting drug use;
- potential behavioural, social and environmental risk factors; and
- accessing appropriate sources of information, support and advice, including testing and treatment information and services.

**RECOMMENDATION 102:**

That NSW Health continue to urge the Commonwealth Department of Health and Family Services to provide funding under the Public Health Outcomes Funding Agreement Incentives Program for a pilot Hepatitis B vaccination program for methadone clients in New South Wales.

**RECOMMENDATION 103:**

That the Minister for Health ensure drug treatment services funded by NSW Health play a more direct and active role in providing information on the prevention of Hepatitis C to injecting drug users.

**RECOMMENDATION 104:**

That NSW Health increase the provision of drug treatment and rehabilitation programs as an effective Hepatitis C preventative strategy.

**RECOMMENDATION 105:**

That the Minister for Health establish a NSW Intersectoral Advisory Committee for Hepatitis C and invite the Ministers for Corrective Services and Police and the Attorney General to join him on that Committee.

**RECOMMENDATION 106:**

That the NSW Intersectoral Advisory Committee for Hepatitis C proposed in Recommendation 105:

- consider the role of drug policy and law reform as a pragmatic measure to limit the transmission of Hepatitis C;
- assess and examine how policies and legislation relating to prohibited drugs (such as the self administration and possession offences, s10 and s12 of the *Drugs Misuse and Trafficking Act, 1985*) can best be revised to serve as effective instruments of health policy and to support public health objectives designed to limit the spread of Hepatitis C;
- encourage public debate about the public health consequences of drug policy reform; and
- examine strategies to improve non-custodial sentencing options.

**RECOMMENDATION 107:**

That the Minister for Health urge his federal counterpart to fund research into issues including:

- reducing the number of injecting drug users;
- improving the effectiveness of treatment for persons using illicit drugs which can be injected;
- development of non-reusable injecting equipment;
- behavioural and ethnographic research into young injectors;
- the effectiveness of bleach and other agents used for decontamination of injecting equipment; and
- the danger of contracting Hepatitis C from the exchange of body fluids

and that the results of such research be used in devising strategies to target those at risk, particularly young injectors.

**RECOMMENDATION 108:**

That the Minister for Corrective Services commission a review of the HIV and Health Promotion Unit to ascertain the staffing needs of the Unit and to ensure the Unit is adequately resourced to meet the information and educational needs of Hepatitis C inmates in the state's correctional system.

**RECOMMENDATION 109:**

That the HIV and Health Promotion Unit ensure all educational strategies employed reflect current health promotion practices. The Committee further recommends that representatives from the Hepatitis C community are consulted along with experts in the field of health education and health promotion in the design of educational material produced by the HIV and Health Promotion Unit.

**RECOMMENDATION 110:**

That the Minister for Health ensure any shortcomings identified in the current review of the methadone maintenance program be considered and acted upon as a matter of priority as a pragmatic public health measure to limit the transmission of Hepatitis C within the state's corrections system and, consequently, the general community.

**RECOMMENDATION 111:**

That the Minister for Health ensure methadone maintenance therapy is available to new prison inmates with a history of injecting drug use to limit the transmission of Hepatitis C within the state's corrections system and, consequently, the general community.

**RECOMMENDATION 112:**

That, recognising the role of tattooing in the transmission of Hepatitis C, the Minister for Corrective Services enable tattoos to be available in hygienic conditions within the state's corrections system.

**RECOMMENDATION 113:**

That the Minister for Corrective Services ensure adequate bleach dispensing machines are available in all correction centres enabling inmates to access bleach freely and anonymously. This should be administered as a Hepatitis C control measure, and should not be linked to drug surveillance.

**RECOMMENDATION 114:**

That the HIV and Health Promotion Unit continue to encourage inmates not to share their razor blades and toothbrushes.

**RECOMMENDATION 115:**

That the NSW Intersectoral Advisory Committee for Hepatitis C proposed in Recommendation 105 give urgent consideration to a range of non-custodial sentencing options such as:

- the use of diversionary sentencing;
- utilisation of drug courts; and
- the inappropriateness of mandatory sentences for minor offences

as a means of reducing the transmission of Hepatitis C in the corrections system.

**RECOMMENDATION 116:**

That the Ministers for Corrective Services and Health establish a medical records database throughout the state's corrections system to facilitate the successful follow-up of inmates and management of their Hepatitis C.

**RECOMMENDATION 117:**

That the Ministers for Corrective Services and Health collaborate to ensure that the Hepatitis B vaccination program operates effectively in every prison and where possible, every alternative community sentencing program.

**RECOMMENDATION 118:**

That the Minister for Health commission a cost effectiveness study of the Hepatitis B vaccination program currently conducted by Corrections Health Service and that the study examine a range of immunisation options including the use of accelerated vaccination schedules.

**RECOMMENDATION 119:**

That the Minister for Corrective Services instruct all correctional centres to purchase and supply only approved barber's shears with detachable heads that can be cleaned readily with bleach and water.

**RECOMMENDATION 120:**

That the Minister for Corrective Services direct that inmates required to clean up blood spills must be provided with adequate protective clothing and appropriate sterilisation solution to minimise their exposure to Hepatitis C.

**RECOMMENDATION 121:**

That the Minister for Corrective Services direct that appropriate educational strategies target non Hepatitis C positive inmates who are at risk of infection during their first few weeks in prison.

**RECOMMENDATION 122:**

That the NSW Intersectoral Advisory Committee for Hepatitis C proposed in Recommendation 105 investigate and report on the appropriateness of introducing a needle and syringe program, modelled on the successful European trials, into the state's correctional system and, if necessary, develop guidelines for the program's implementation.

**RECOMMENDATION 123:**

That the Department of Corrective Services design, develop and implement an in-service training course for prison officers made up of education modules on harm minimisation and that adequate resources be made available to fund the implementation of the modules. The Committee further recommends that the Minister for Corrective Services direct all prison officers to undertake the proposed in-service training course on harm minimisation.

**RECOMMENDATION 124:**

That Corrections Health Service make available a range of drug withdrawal strategies to inmates seeking to give up their drug habit.

**RECOMMENDATION 125:**

That the Ministers for Health and Corrective Services direct that a policy addressing prevention of Hepatitis C within the state's correctional system and the role played by drugs in the transmission of Hepatitis C be collaboratively developed between the two departments and that the policy be included in the NSW Hepatitis C Policy Statement proposed in Recommendation 28. The Committee further recommends that the two departments also develop strategies to prevent Hepatitis C transmission in the state's

corrections system and incorporate these strategies into the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

**RECOMMENDATION 126:**

That the Minister for Health, through the forum of the Australian Health Ministers' Council, encourage the Australian Council on Health Care Standards to include the inspection of documentation verifying implementation of a Hepatitis B vaccination program for staff (excluding confidential staff records) in the hospital accreditation procedures.

**RECOMMENDATION 127:**

That the Minister for Health, through the forum of the Australian Health Ministers' Council, urge his federal, state and territory counterparts to consider the adoption of national infection control standards. The Committee further recommends that the Minister for Health propose the NHMRC's guidelines for the prevention of transmission of infectious diseases entitled *Infection Control in the Health Care Setting* (1996) be considered as the basis for national infection control standards.

**RECOMMENDATION 128:**

That, within the context of the Australian Health Ministers' Council, the Minister for Health urge his federal, state and territory counterparts to consider the adoption of standard procedures for endoscopic units including sterilisation, staff training and use of disposable medical appliances as part of the hospital accreditation process.

**RECOMMENDATION 129**

That the Minister for Health encourage his federal counterpart to design and introduce a national community education Hepatitis C campaign. The Committee further recommends that NSW Health fully support the introduction of a community based Hepatitis C education campaign within NSW and provide whatever assistance may be required.

**RECOMMENDATION 130:**

That the national community education Hepatitis C campaign proposed in Recommendation 129 include a component about the role of preventative strategies such as the methadone maintenance therapy program and the needle and syringe program in limiting the transmission of Hepatitis C.

**RECOMMENDATION 131:**

That the Minister for Health urge his federal counterpart support and fund research into the social factors which increase the risk of contracting Hepatitis C. The Committee further recommends that the Minister for Health encourage his federal counterpart to utilise the results of sound social research in the design and introduction of the community based education Hepatitis C campaign proposed in Recommendation 129.

**RECOMMENDATION 132:**

That the Premier invite his Parliamentary colleagues, from both Houses and all political parties, to form a Hepatitis C Parliamentary Liaison Group. The role of the Liaison Group would be to advocate and support Hepatitis C related policies within the political domain with an overall objective to limit the spread of Hepatitis C in the general community and the corrections system.