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Review of Health Services Available for Persons who Contracted Hepatitis C through the Administration within the State of Blood or Blood Products. Implementation of Recommendations.

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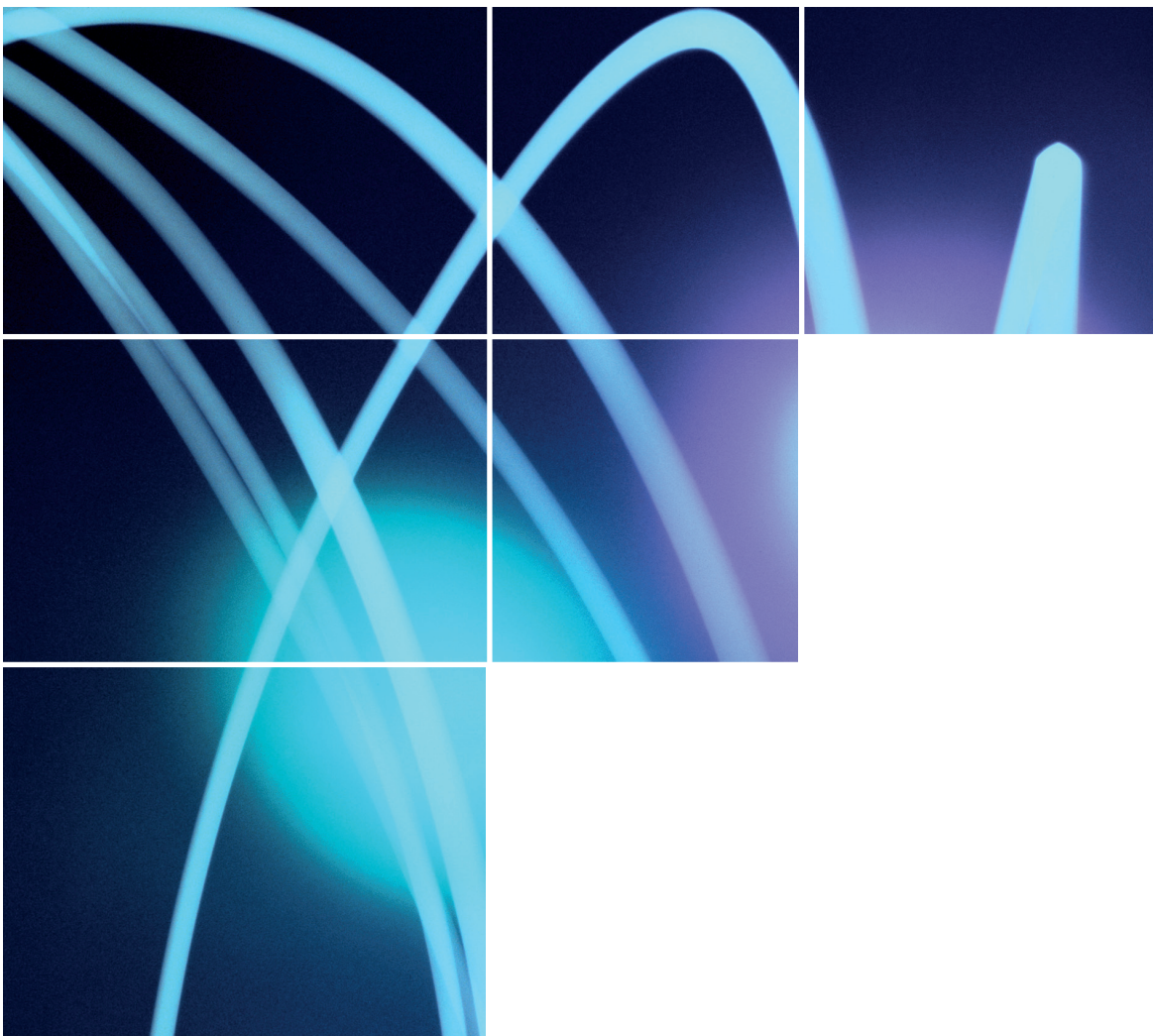
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Review of Health Services Available for Persons who Contracted Hepatitis C through the Administration within the State of Blood or Blood Products Implementation of Recommendations



Consultative Council on Hepatitis C

September 2005

**REVIEW OF HEALTH SERVICES FOR PERSONS WHO
CONTRACTED HEPATITIS C THROUGH THE
ADMINISTRATION WITHIN THE STATE OF BLOOD
AND BLOOD PRODUCTS

IMPLEMENTATION OF RECOMMENDATIONS**

Review conducted by:

**Professor Hannah McGee
Dr Anne Hickey
Ms Marie Brady
Dr Katherine Gavin**

**Health Services Research Centre
Psychology Department
Royal College of Surgeons in Ireland
&
Institute of Public Administration**

September 2005

Foreword

In March 2000 the Consultative Council published its *Review of Health Services Available for persons who Contracted Hepatitis C through the administration within the State of Blood or Blood Products*. At that time the Council committed itself to ensuring that the Review would be a positive and dynamic tool in assisting health service providers, the Department of Health and Children and the support groups to identify, provide, monitor and improve the services required by persons infected with Hepatitis C through the administration within the State of infected blood and blood products.

The Report examines progress on the recommendations published in 2000, and recognizes the evolution in service needs since then with the addition of 4 new recommendations. The Report will assist health service providers, the Department of Health and Children and the support groups to continue working together to ensure that the future service needs of this Hepatitis C group are met. It is timely that this review has come at a time when the health services are entering a new phase of restructuring and renewal. The Consultative Council welcomes this process and is confident that it will bring benefits to both service users and service providers. The Council has assured the Health Service Executive and the National Hospitals Office that we will be happy to co-operate with them and to continue playing a positive role in shaping Hepatitis C services for this cohort of patients in the future.

As with the first Review the four support groups - Positive Action, Transfusion Positive, the Irish Haemophilia Society and the Irish Kidney Association - all of which are represented on the Consultative Council, are to be commended for the important role they play, and for encouraging their members to participate in this progress report.

I would like to thank the authors of the report, Professor Hannah McGee and Dr. Anne Hickey and their research team, Ms Marie Brady and Dr Katherine Gavin. I also want to thank all the members of the Consultative Council who gave the benefit of their expertise during this review.

On behalf of the Council, I am pleased to present this report to the Tánaiste and Minister for Health and Children, Mary Harney T.D. and look forward to continuing the Council's positive relationship with the Tánaiste and her officials in the coming years.



Dr Elizabeth Kenny
Chair, Consultative Council on Hepatitis C
September 2005



The Consultative Council on Hepatitis C

Membership List

Ms Paula Kealy	<i>Positive Action</i>
Ms Siobhan O'Connor	<i>Positive Action</i>
Ms Mary Rowe	<i>Transfusion Positive</i>
Mr Michael Madigan	<i>Transfusion Positive</i>
Mr Mark Murphy	<i>Irish Kidney Association</i>
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Ms Ann Broekhoven	
Professor Aiden McCormick	
Professor Cliona O'Farrelly	
Ms Ann McGrane	
Mr John Cullinane	
Ms Margaret Scarry	
Mr John Murphy	
Dr Elizabeth Kenny (Chair)	
Mr Paul O'Donoghue	
Mr Ian Carter	



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SECOND REVIEW: OVERVIEW

This review was commissioned by the Consultative Council on Hepatitis C, which was established to advise and make recommendations to the Minister for Health and Children on all aspects of hepatitis C including the organisation and delivery of services for persons with hepatitis C. The Health Services Research Centre (HSRC) at the Department of Psychology, Royal College of Surgeons in Ireland and the Institute of Public Administration (IPA) conducted the review. The HSRC is a multidisciplinary centre established in 1997 to promote quality health care delivery in Ireland. The IPA is the Irish national centre for development of best practice in public administration and public management. The review was directed by Professor Hannah McGee and Dr Anne Hickey. Professor McGee is a health psychologist and HSRC director. Dr Hickey is a health psychologist in the RCSI. The other two team members were Dr Katherine Gavin, independent healthcare management consultant and Ms Marie Brady, Senior Health Specialist in the IPA. The review was completed between July 2004 and January 2005.

As the Second Review of Health Services for Persons who contracted Hepatitis C through the Administration within the State of Blood or Blood Products, its brief was to evaluate progress on the recommendations made in the First Review and ascertain new and ongoing priorities for the future. Findings from the Review are summarised briefly overleaf with the detailed rationale for the recommendations provided throughout the report. Much progress has been achieved in the five years since the First Review. This progress has been achieved through considerable coordination of effort and focus by all concerned – staff in the health service, the support organisations and the Consultative Council on Hepatitis C at the Department of Health and Children. All of the major recommendations of the First Review remain relevant. A number have achieved a satisfactory level of management and now require ongoing maintenance. A further set of recommendations has been more difficult to fully effect. These are identified here as priorities for the next phase of service delivery. Acknowledging the evolving nature of the condition and ageing of the population being served, four new areas of focus have also been identified. The summary overleaf outlines the recommendations of this Second Review in this format: those original recommendations which have been satisfactorily achieved and which now need to be maintained; those original recommendations which require further progress as a priority; and those new recommendations which have been identified from the Second Review. They are summarised as priority recommendations and recommendations needing oversight or maintenance.

In conclusion, much has been achieved in a focused partnership approach among health services providers, support organisations and a Department of Health and Children supported Consultative Council. Some of the initiatives undertaken to address challenges can benefit other sectors in the health system. Equally, some of the ongoing concerns are challenges within the wider health system. These need broader leadership to ensure that a specific area like hepatitis C can obtain the service delivery to which its users are entitled.



ACKNOWLEDGEMENTS

This report was completed with the ready assistance of health service providers, and of Hepatitis C support organizations. The researchers gratefully acknowledge the assistance of all those whom they consulted in the preparation of the report (a full list is included in Appendix 2.1). They particularly appreciate the assistance of the support organizations who coordinated the distribution and return of survey questionnaires from their members. They are also grateful to the team in the Department of Health and Children, and to the Council's Steering Committee for their input, and for useful feedback on the draft stage of the report.

EXECUTIVE SUMMARY

Background

- A cohort of persons who received blood or blood products in the late 1970s or in the late 1980s/early 1990s from the State-provided services were infected iatrogenically with hepatitis C. Following exposure of the problem and extended pressure from support groups formed to address the concerns of this group, a change in legislation (the Health (Amendment) Act, 1996) provided statutory entitlements to a range of primary health care services for the group. Specialist hepatology services were also established in eight designated hospitals nationwide to provide services for this group.
- In 1996, a Consultative Council on Hepatitis C was established by the Minister for Health to advise and make recommendations to the Minister on all aspects of care of this hepatitis C group. It commissioned a first review on service delivery in 1998. This (hereafter called the ‘First Review’) was published in 2000. It contained 12 recommendations that were accepted by the Department of Health and Children. Among them was the recommendation to repeat the review after three years. This project (hereafter called the ‘Second Review’) undertakes a repeat assessment of service delivery. Specific objectives are to consider the implementation of the 12 recommendations and to identify new issues emerging as significant since the First Review.

Review methodology

- Consultation with hepatitis C-infected individuals and support organisation representatives: interviews were conducted with management teams of the four support organisations (Positive Action, Transfusion Positive, Irish Haemophilia Society and Irish Kidney Association). These interviews informed development of a structured questionnaire that was distributed as an anonymous postal survey by organisations to their membership (N=476; 40% response; see table ES1). While this sample was not a random sample of the hepatitis C population, as was the case in the First Review, the majority of respondents reported having active hepatitis C. Thus, survey results are likely to represent views on services from those who use services most often.
- Health services personnel interviews: those consulted or interviewed as part of this review included staff from all eight relevant hospitals (medical and administrative staff in hepatology units), hepatitis C liaison officers of the 11 (former) health boards (now Health Services Executive)(HSE) areas, and staff at the Department of Health and Children and the HSE Health Protection Surveillance Centre (former National Disease Surveillance Centre). In addition, liaison officers provided board level data on primary care service use.

Table ES1: Demographic profile of persons with hepatitis C as a result of State-contaminated blood supplies and participating in the survey

	ROUTE OF INFECTION				Total N=476 (response: 40%)
	Anti-D N=332/736(res ponse: 45%)	Haemophilia N=19/210 (response: 9%)	Renal N=3/25 (response:12%)	Transfusion N=122/220 (response: 55%)	
<i>Age-median (range) [years]</i>	54 (25-70+)	45 (<25-59)	45 (<25-54)	58 (14-91)	54 (<25-70+)
<i>Sex (% men) N (male:female)</i>	(0%) 0:332	(89%) 17:2	(100%) 1:0	(25%) 30:92	(10%) 48:426
<i>Number of children: median (range)</i>	4 (0-11)	2 (0-5)	2 (0-2)	3 (0-10)	3 (0-11)
<i>Distance (miles) from hospital, round trip - Median (range)</i>	52 (0-300+)	70 (0-300+)	280 (150-299)	60 (0-300+)	60 (0-300+)

Results

Results are presented in the following 2 tables.

Table 2 considers the results as they relate to the original 12 recommendations and to new and important issues emerging since the First Review. Each of the 12 recommendations from the First Review is outlined in the first column, followed by a brief summary of progress (second column). Following this, the recommendation from the Second Review is outlined (third column). For clarity, all First Review Recommendations are listed as numbers (1,2 etc) and all Second Review Recommendations are listed using letters (A, B etc).

Table ES3 contains new recommendations identified as a result of the review. These reflect the evolving nature of the condition and the changing needs of patients as they continue to live with their condition.

The overall focus of the Second Review is to determine progress on First Review recommendations by combining differing sources of information from the various stakeholders concerned. To do this, a substantial body of information was collected and is summarized throughout the report to illustrate the basis of the conclusions from the Second Review. Figure ES1 summarises in a particularly salient way the overall sense of the Second Review's findings. It is an outline of views of over 400 service users regarding what changes, if any, they felt had taken place in their healthcare since 1999 (i.e. over the five years since the First Review). Across ten services assessed, a significant proportion (42-67%) felt that they had improved in that time. Reports of disimprovement were very low (8% at most) with many also reporting that quality was similar on both occasions. In terms of the wider context, 40% felt that public awareness of their condition had improved in that timeframe and 71% judged access to information as improved. Finally, financial cover for medical care costs were deemed to be improved by 57% with only 4% reporting them as worse by the time of the Second Review.

Figure ES1: Participant perceptions of changes in health and related services since the First Review

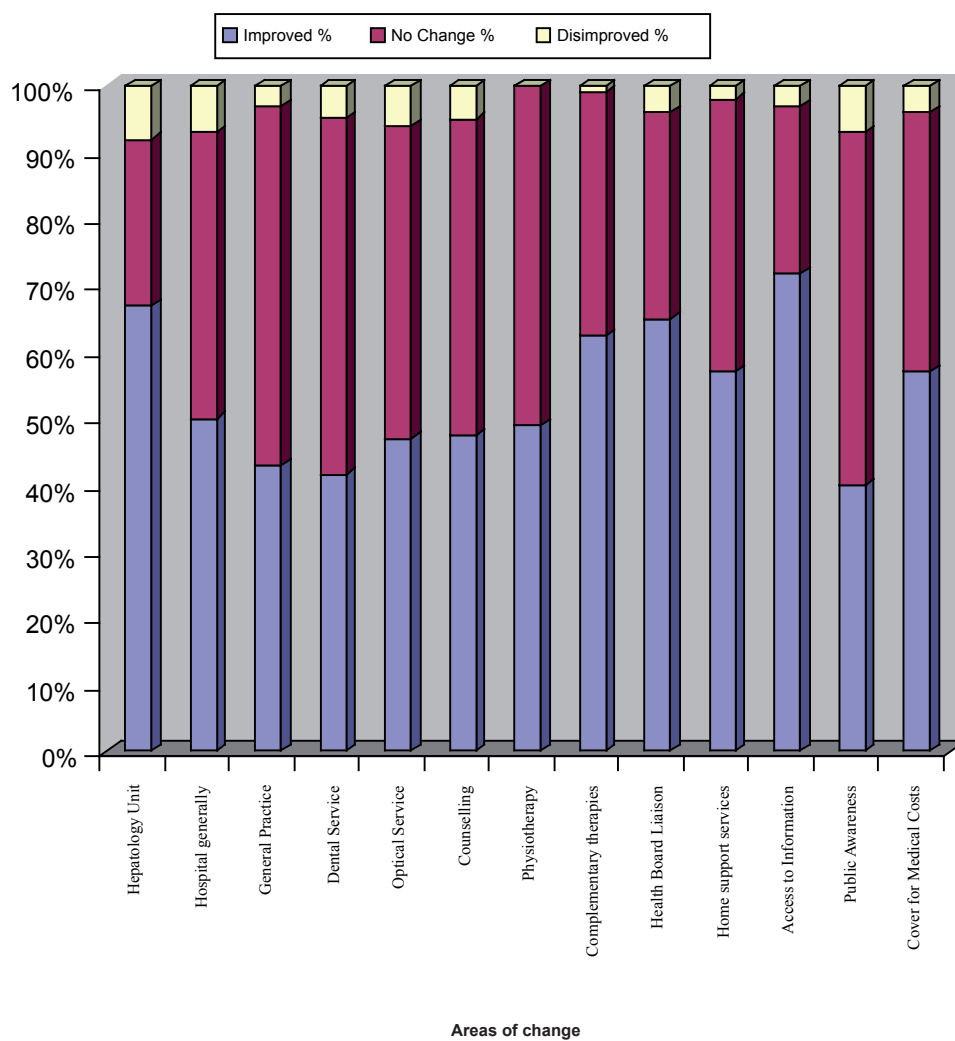


TABLE ES2: UPDATED RECOMMENDATIONS

Original Recommendations	Progress Summary	Second Review Recommendation
<p>Recommendation 1</p> <p><i>That a committee be established to agree treatment protocols (including liver biopsy procedures and scoring, and administration of anti-viral therapy) for this particular group. The committee should comprise the medical consultants with primary responsibility for this group of patients and be chaired on a rotating basis.</i></p>	<p>This recommendation was activated and the consultant group has met but not recently. The continuing importance of the group's work was emphasised by many of those consulted for the Second Review. A mechanism to ensure a focused agenda and facilitation of meetings to this agenda is needed.</p>	<p>Recommendation A <u>Recommend as a priority</u></p> <p><i>That the Medical Consultant Sub-Committee meet at least twice yearly to provide expert advice to the Consultative Council on issues identified by the Council. It is further recommended that the Consultative Council provide administrative support to the Sub-Committee.</i></p>
<p>Recommendation 2</p> <p><i>That the system whereby patients are referred by their consultant hepatologist to another speciality be regularised to facilitate Hepatology Unit staff in making priority referrals in accordance with the 'two-week' rule. A comprehensive referral system for physiotherapy should be established to ensure that it is available to all who require it.</i></p>	<p>This recommendation has been given considerable emphasis but requires ongoing attention. In some locations the 'two-week rule' regarding referral to another specialty has worked well while in others there are considerable challenges. This in part reflects the fact that staff use informal networks insofar as they are available to them to have this rule implemented. No other group of patients within the health system has protected entitlements to medical consultant appointments within a specified timeframe. In parallel, many personnel outside of the hepatology service have concerns about patient equity in delivering on this rule. Mechanisms to minimise staff time in delivering</p>	<p>Recommendation B <u>Recommend as a priority</u></p> <p><i>That the system whereby patients are referred by their consultant hepatologist to another speciality be regularly reviewed in each hospital so that hospital procedures facilitate Hepatology Unit staff in making priority referrals in accordance with the two-week rule.</i></p>

Original Recommendations	Progress Summary	Second Review Recommendation
	on the rule are needed. Problems with access to physiotherapy appointments have been resolved since the First Review. This has been achieved mainly by allowing use of, and reimbursement for, private physiotherapy services. In tandem, this has meant more choice, including local access to physiotherapy services.	
Recommendation 3 <i>That guidelines be developed for the management of death, including funeral arrangements, so that the necessary safe practices are understood and accepted by all concerned.</i>	Guidelines on the management of death have been in development for some time, but without a responsible agency and delivery date. An appropriate agency has been identified and will be given responsibility to deliver on this recommendation.	Recommendation C <u>Recommend as a priority</u> <i>That guidelines be developed for the management of death, including funeral arrangements, so that the necessary safe practices are understood, accepted and followed by all concerned</i>
Recommendation 4 <i>That health board liaison officers meet on a regular basis to ensure uniformity and continuity in the provision of primary health care services.</i>	This recommendation is working well. Liaison officers meet together and with Department of Health and Children, and support organisation representatives, on a regular basis. Meetings monitor, and have improved, the level of consistency of service provision nationally. The meetings provide a valuable forum for sharing information.	Recommendation D <u>Recommend Maintenance</u> <i>That health board liaison officers continue to meet on a regular basis to ensure ongoing uniformity and continuity in the provision of primary health care services.</i>
Recommendation 5 <i>That health board liaison officers ensure choice of counsellors and counselling locations in all health board areas.</i>	This recommendation has been addressed such that there is now a choice among a number of counsellors in all Health Service Executive (former health board) areas.	Recommendation E <u>Recommend Maintenance</u> <i>That Health Service Executive liaison officers continue to ensure choice of counsellors and counselling locations in all health regions.</i>

Original Recommendations	Progress Summary	Second Review Recommendation
<p>Recommendation 6</p> <p><i>That a general training programme for all home support providers be available. This programme must have as a basis an agreed strategy regarding the balance to be achieved between duty of care to the provider and the right to confidentiality of health information of the recipient.</i></p>	<p>This recommendation is still challenging. Home support providers are mainly identified by those seeking home support, rather than being provided by the Health Service Executive (former health board) area. This has been a very good solution to the challenge of confidentiality. However, this mechanism raises important duty of care issues (see Recommendation 7).</p>	
<p>Recommendation 7</p> <p><i>That the issues surrounding the difficulty in recruitment of home support providers, including remuneration issues, be reviewed to ensure availability of the service to all who require it.</i></p>	<p>Payment rates for home supports have been regularised since the First Review. However, the focus of this recommendation has evolved into a more complex issue in recent years. Recruitment of home support providers <i>per se</i> is not problematic since individuals can self-select or accept a Health Service Executive area appointed home support provider. However, remuneration of directly-employed home supports has raised issues of transparency and accountability of health service funds, and issues of employer responsibility and liability for both individuals recruiting the home support providers and the health system (as also outlined in Recommendation 6). This needs to be resolved as a priority</p>	<p>Recommendation F <u>Recommend as a priority</u></p> <p><i>That the position of home support provider be regularised with due regard for patient confidentiality, while also ensuring statutory legal requirements in relation to employment are fulfilled.</i></p>
<p>Recommendation 8</p> <p><i>That staff in all primary care disciplines dealing with this patient group (including general practitioners, dentists and pharmacists) be adequately informed about both the actual risk of transmission of Hepatitis C and the guidelines on</i></p>	<p>This recommendation has been addressed by numerous educational and communication activities since the First Review. Changing service personnel means that updating staff on clinical and service entitlement aspects of this condition will continue to be necessary.</p>	<p>Recommendation G <u>Recommend Maintenance</u></p> <p><i>That staff in all primary care disciplines dealing with this patient group (including general practitioners, dentists and pharmacists) continue to be adequately informed about the actual risk of transmission of hepatitis C and the guidelines on</i></p>

Original Recommendations	Progress Summary	Second Review Recommendation
<p><i>universal precautions against transmission of infection; this is to ensure that such patients are treated in a sensitive manner.</i></p>		<p><i>universal precautions against transmission of infection; this is to ensure that such patients are treated in a sensitive manner. It is further recommended that primary care service providers continue to be made aware of the potential to contact the health board liaison officer, if necessary.</i></p>
<p>Recommendation 9</p> <p><i>That the role of complementary or alternative therapies in the management of Hepatitis C be reviewed as part of a wider framework of evaluation of the use of such therapies in the Irish health system.</i></p>	<p>Progress on this recommendation has been constrained both by European developments and by challenges in relation to registration of professional bodies in complementary therapy. Meanwhile the use of, and interest in using, complementary therapies has increased significantly in the hepatitis C cohort since the time of the First Review. This task needs to be addressed as an important medium-term objective for this group and users of the health service more generally. There needs to be advocacy for change more generally rather than trying to find a hepatitis C-specific solution to this issue.</p>	<p><u>Recommendation H</u> <u>Recommend as a priority</u></p> <p><i>That a review of the role of complementary or alternative therapies in the management of hepatitis C be advocated for as part of a wider framework of evaluation of the use of such therapies in the Irish health system.</i></p>
<p>Recommendation 10</p> <p><i>That a national database be established for research purposes; this to be located at an independent coordinating agency and run in association with relevant groupings.</i></p>	<p>This recommendation has been implemented. Extraction of baseline details from patients' hospital charts began in December 2004.</p>	<p><u>Recommendation I</u> <u>Recommend Maintenance</u></p> <p><i>That the national database be maintained for research and service planning; this to continue to be located at an independent coordinating agency; to be run in association with relevant groupings; and to work with others to maintain and increase database coverage of the relevant population.</i></p>

Original Recommendations	Progress Summary	Second Review Recommendation
<p>Recommendation 11</p> <p><i>That assurances be given that adequate funding and resources will continue to be provided to ensure a quality health care service for this patient group.</i></p>	<p>Funding has remained acceptable to the various hepatitis C constituencies within the constraints of annual budget management in the health services. While there was little concern from those consulted that funding would be a problem, based on experience to date, changing population characteristics including ageing of the patient group mean that funding demands will increase in the coming years. This is an important area to review on an ongoing basis.</p>	<p>Recommendation J <u>Recommend Maintenance</u></p> <p><i>That continuing assurances be given that adequate funding and resources will be provided to ensure a quality health care service for this patient group.</i></p>
<p>Recommendation 12</p> <p><i>That progress on the recommendations of this Review be monitored on an annual basis for three years with a report summarising progress to be completed at the end of this period. Progress to be monitored by a sub-committee of the Consultative Council on Hepatitis C.</i></p>	<p>This recommendation has been addressed in many ways over the past few years. It continues to be important but a series of mechanisms to ensure it happens are now in place.</p>	<p>Recommendation K <u>Recommend Maintenance</u></p> <p><i>That progress on the recommendations of this Review be monitored on an ongoing basis for five years with a report summarising progress to be completed at the end of this period.</i></p>

TABLE ES3: NEW RECOMMENDATIONS

Emerging Issue	Recommendation
<p>HOME NURSING SERVICES:</p> <p>Home nursing was identified as a service that will increase considerably in the medium to long-term, as the patient cohort becomes older. A pilot scheme is about to commence in the Health Service Executive - Eastern Region (former Eastern Regional Health Authority). It is recommended that a home nursing service for hepatitis C be established on a national basis.</p>	<p>Recommendation L <u>New recommendation to prioritise</u></p> <p><i>That a home nursing service for hepatitis C be established nationally in anticipation, and in advance of, increased demand.</i></p>
<p>HEALTH PROMOTION ACTIVITIES:</p> <p>Lack of availability of health professionals to provide key health promotion intervention was identified as an important current issue with emerging implications, e.g., concerning diabetes. Difficulty in accessing dietitians was identified as widespread. It is recommended that access to necessary health care professionals be organised.</p>	<p>Recommendation M <u>New recommendation to address</u></p> <p><i>That access to necessary health care professionals be organised so that appropriate, tailored health promotional interventions can be provided to promote health and well-being.</i></p>
<p>ONGOING MONITORING OF PROGRESS ON HEPATITIS C:</p> <p>Given the evolving nature of hepatitis C treatment and management, there is a need to monitor developments in the context of the Irish hepatitis C cohort. Ongoing monitoring is likely to be the task of many constituencies, e.g., the Medical Consultant Sub-Committee, the Steering Committee of the national Hepatitis C Database or support organisations. It is recommended that ongoing monitoring of emerging needs and scientific developments be conducted.</p>	<p>Recommendation N <u>New recommendation to address</u></p> <p><i>That ongoing monitoring of emerging needs be conducted, alongside tracking of emerging therapies and changes in practice</i></p>
<p>CHILDREN AND YOUNG ADULT NEEDS:</p> <p>Most of the small cohort currently attending specialist children's service for iatrogenic hepatitis C is now in their teenage years and in good health. Emerging concerns relate to intimacy and relationship issues in the context of an infectious condition. Challenges of young adulthood for this group need to be anticipated and addressed proactively</p>	<p>Recommendation O <u>New recommendation to address</u></p> <p><i>That the challenges of young adulthood for this group be anticipated in order to assist professionals, young people themselves and their families in addressing their emerging concerns.</i></p>

CONCLUSIONS

There has been considerable progress in addressing the 12 recommendations of the First Review in the last five years. This reflects significant commitment including financial investment and increasing cooperation across all sectors over time. Many of the lessons learned can be usefully transferred to other aspects of the health system. Impending challenges in hepatitis C management in this specific population are in part a result of, or are attenuated by, the challenges of ageing for the group. The Consultative Council on Hepatitis C provides a valuable coordinating function for ongoing implementation and evaluation of the service needs of this hepatitis C population into the foreseeable future.

Table ES4: SECOND REVIEW: SUMMARY OF RECOMMENDATIONS

1) RECOMMENDATIONS FULLY ADDRESSED SINCE FIRST REVIEW: NEED TO BE MAINTAINED

Recommendation D: That health board liaison officers continue to meet on a regular basis to ensure ongoing uniformity and continuity in the provision of primary health care services.

Recommendation E: That Health Service Executive liaison officers continue to ensure choice of counsellors and counselling locations in all health regions.

Recommendation G: That staff in all primary care disciplines dealing with this patient group (including general practitioners, dentists and pharmacists) continue to be adequately informed about the actual risk of transmission of hepatitis C and the guidelines on universal precautions against transmission of infection; this is to ensure that such patients are treated in a sensitive manner. It is further recommended that primary care service providers continue to be made aware of the potential to contact the health board liaison officer, if necessary.

Recommendation I: That the national database be maintained for research and service planning; this to continue to be located at an independent coordinating agency; to be run in association with relevant groupings; and to work with others to maintain and increase database coverage of the relevant population.

Recommendation J: That continuing assurances be given that adequate funding and resources will be provided to ensure a quality health care service for this patient group.

Recommendation K: That progress on the recommendations of this Review be monitored on an ongoing basis for five years with a progress report to be completed at the end of this period.

2) RECOMMENDATIONS NOT FULLY ADDRESSED SINCE FIRST REVIEW: ADDRESS AS PRIORITY

Recommendation A: That the Medical Consultant Sub-Committee meet at least twice yearly to provide expert advice to the Consultative Council on issues identified by the Council. It is further recommended that the Consultative Council provide administrative support to the Sub-Committee.

Recommendation B: That the system whereby patients are referred by their consultant hepatologist to another specialty be regularly reviewed in each hospital so that hospital procedures facilitate Hepatology Unit staff in making priority referrals in accordance with the two-week rule.

Recommendation C: That guidelines be developed for the management of death, including funeral arrangements, so that the necessary safe practices are understood, accepted and followed by all concerned.

Recommendation F: That the position of home support provider be regularised with due regard for patient confidentiality, while also ensuring statutory legal requirements in relation to employment are fulfilled.

Recommendation H: That a review of the role of complementary or alternative therapies in the management of hepatitis C be advocated for as part of a wider framework of evaluation of the use of such therapies in the Irish health system.

NEW RECOMMENDATION: ADDRESS AS PRIORITY

Recommendation L: That a home nursing service for hepatitis C be established nationally in anticipation, and in advance of, increased demand.

3) NEW RECOMMENDATIONS: NEED TO BE ADDRESSED

Recommendation M: That access to necessary health care professionals be organised so that appropriate, tailored health promotional interventions can be provided to promote health and well-being.

Recommendation N: That ongoing monitoring of emerging needs be conducted, alongside tracking of emerging therapies and changes in practice.

Recommendation O: That the challenges of young adulthood for this group be anticipated in order to assist professionals, young people themselves and their families in addressing their emerging concerns.

Chapter 1

INTRODUCTION AND TERMS OF REFERENCE

Background to the Second Review

Following identification of blood contamination at the Blood Transfusion Service in 1994, a national screening programme identified over 1600 people as infected with hepatitis C from State-provided blood and blood products from the late 1970s to the early 1990s. The then Department of Health committed to a variety of methods to ensure high quality and prompt services to those infected. (A brief history of this issue is provided in Appendix 1.1). A national review of service use and quality was commissioned in 1998 by a Consultative Council on Hepatitis C established by the Department of Health and Children. This review involved extensive consultation with those concerned: health professional, policy and administrative staff in secondary and primary healthcare care settings; support organisations representing those affected; and those who had been infected themselves. Among those interviewed were hepatology staff at all seven hospitals designated as specialist centres for adults with hepatitis C, designated liaison staff in each health board (now called Health Service Executive Area), primary healthcare representatives and persons infected with State-provided blood or blood products [N= 28 persons with hepatitis C participating in four support organisation-specific focus groups enabled identification of key issues for their members. Following this, 132 persons identified through hospital patient lists representing all routes of infection completed extensive interviews]. In addition, a quarter of all hospital charts were reviewed (N=388) and a national random sample of general practitioners treating hepatitis C patients (N=85) were surveyed.

The result was published as a report entitled *Review of health services available for persons who contracted Hepatitis C through the administration within the State of blood or blood products* (McGee, Hickey, Smith & Byrne (2000). The published Review included 12 recommendations and was accepted by the Department of Health and Children. The Review was published and disseminated widely among the relevant constituencies. Each of these was asked to address recommendations specifically relevant to them. This exercise was facilitated by the then incoming Consultative Council on Hepatitis C (Council 2000-2003: Chair – Dr Ruth Barrington) and by the present Council (Council 2003-2006: Chair – Dr Elizabeth Kenny).

The last recommendation of the Review (Recommendation 12) advised a follow-up in three years to assess progress with the implementation of the other recommendations. After three years, the then Consultative Council initiated a consultation and tendering process to undertake this follow-up. A team from the Royal College of Surgeons in Ireland (Health Services Research Centre) and the Institute of Public Administration were commissioned to undertake the Second Review. Consultation for the review was undertaken in the second half of 2004.

The recommendations of the 2000 Review (hereafter called the First Review) are as follows:

1. That a committee be established to agree treatment protocols (including liver biopsy procedures and scoring, and administration of anti-viral therapy) for this particular group. The committee should comprise the medical consultants with primary responsibility for this group of patients and be chaired on a rotating basis.
2. That the system whereby patients are referred by their consultant hepatologist to another specialty be regularised to facilitate Hepatology Unit staff in making priority referrals in accordance with the 'two-week' rule. A comprehensive referral system for physiotherapy should be established to ensure that it is available to all who require it.
3. That guidelines be developed for the management of death, including funeral arrangements, so that the necessary safe practices are understood and accepted by all concerned.
4. That health board (now Health Service Executive) liaison officers meet on a regular basis to ensure uniformity and continuity in the provision of primary health care services.
5. That health board (now Health Service Executive) liaison officers ensure choice of counsellors and counselling locations in all Health Service Executive areas.
6. That a general training programme for all home support providers be available. This programme must have as a basis an agreed strategy regarding the balance to be achieved between duty of care to the provider and the right to confidentiality of health information of the recipient.
7. That the issues surrounding the difficulty in recruitment of home support providers, including remuneration issues, be reviewed to ensure availability of the service to all who require it.
8. That staff in all primary care disciplines dealing with this patient group (including general practitioners, dentists and pharmacists) be adequately informed about the actual risk of transmission of hepatitis C and the guidelines on universal precautions against transmission of infection; this is to ensure that such patients are treated in a sensitive manner.
9. That the role of complementary or alternative therapies in the management of hepatitis C be reviewed as part of a wider framework of evaluation of the use of such therapies in the Irish health system.
10. That a national database be established for research purposes; this to be located at an independent coordinating agency and run in association with relevant groupings.

11. That assurances be given that adequate funding and resources will continue to be provided to ensure a quality health care service for this patient group.
12. That progress on the recommendations of this Review be monitored on an annual basis for three years with a report summarising progress to be completed at the end of this period. Progress to be monitored by a sub-committee of the Consultative Council on Hepatitis C.

Overall aim of the Second Review:

To assess the implementation of recommendations on management of hepatitis C as advised and accepted in a Review conducted in the year 2000 and to identify any new areas of concern for those infected with State-provided blood or blood products.

Specific objectives of the Second Review:

- 1) To examine the implementation of specific recommendations made in the First Review (2000); and
- 2) To identify healthcare issues of concern to persons with blood product-related hepatitis C infection which may have emerged since completion of the First Review.

The methods of conducting this Review are outlined in Chapter 2. Before this, an outline of the most pertinent changing external circumstances over the five-year period since the conduct of the First Review is important.

Changing external environment between Reviews

A number of factors, which are distinct from the coverage of recommendations but relevant to overall consideration of management of hepatitis C, have changed since information was collected for the First Review. These involve changes in legal, clinical management and policy related issues.

In the legal context, hepatitis C has become a notifiable condition. This means that from January 2004 all cases which come to the attention of medical practitioners or medical laboratory directors must be notified to the Health Protection Surveillance Centre (HPSC). The HPSC is the national centre for surveillance of communicable diseases. It was established in 1998 by the Health Service Executives and the Department of Health and Children.

Another legal change has been the introduction of the concept of ‘loss of consortium’ in the Hepatitis C Compensation Tribunal (Amendment) Act 2002. This Act entitles spouses and partners of those with hepatitis C from State-provided blood to make claims to the Compensation Tribunal for loss of consortium. Consortium has been defined as “companionship, the rendering of services, sexual intercourse and affectionate relations between spouses”. The Act indicates that those married to or living with a person infected through State-provided blood for a continuous period of not less than three years may bring a claim in respect of the loss of consortium of the

person, including impairment of sexual relations with the person, arising from the risk of transmission of hepatitis C¹. The Act specifically covers compensation for loss of consortium as a result of risk of transmission but not as a result of symptoms or illness of the infected person (which it is assumed is compensated for elsewhere in the provisions of the initial Act). Losses must be brought within three years of the loss of consortium or by October 9th 2005 (whichever date is later).

A third legal change, negotiated and proposed to Government by the Tanaiste and Minister for Health and Children Mary Harney TD in early 2005, is legislation to facilitate life insurance and mortgage insurance cover for those infected through State-provided blood. This proposal is currently awaiting Department of Finance approval.

In terms of clinical management, some developments in evidence at the time of the first Review have now become established practice. In particular, combination therapy [i.e. peg-interferon alpha and ribavirin] has been established as standard care for those with moderate to severe chronic hepatitis C over the period between reviews (in the UK the National Institute for Clinical Excellence formally recommended its use in NHS settings for patients aged 18 years and over in January 2004 (NICE, 2004).

In policy terms, the topic of hepatitis C more generally has received increasing attention in a number of countries because of the serious public health implications of its spread. In Ireland, the level of hepatitis C in injecting drug users has been noted as higher than that of equivalent groups in other countries, e.g., 52% of recent users (i.e., used only within the last 2 years) and 84% of longer-term injecting drug users (Smith et al, 1999; Smith et al, 1995). Levels for injecting drug users in prisons is even higher (72-81%) (Allwright et al., 2000; Long et al., 2001).

In the UK, hepatitis C has been described as the ‘silent epidemic’, with an estimated 0.4% (c.200,000 people) with chronic hepatitis C infection but less than 20% of these identified. Most of these people have been infected thorough injecting drug misuse - it is estimated that about twice as many men as women are infected in the UK. A number of policy statements, including summaries of these statistics, have been issued by their Departments of Health, including the *Hepatitis C Action Plan for England* (2004) and *Hepatitis C: Essential Information for Professionals and Guidance on Testing* (2004). These are part of a broader UK plan of ‘intensified action’ on infectious diseases, which have been seen as a ‘Cinderella service’ within the wider health system. The focus in such national strategies has been as much or more on prevention and diagnosis of hepatitis C in this wider population as on treatment initiatives.

A payment system for those infected through the UK’s National Health Service (NHS) has recently been agreed. On January 23rd 2004, the Secretary of State for England agreed an *ex gratia* payment scheme for those ‘inadvertently infected with hepatitis C as a result of NHS treatment with blood or blood products’. Those eligible are those infected prior to September 1991) (when NHS screening of blood for

¹ Sexual transmission of hepatitis C is possible but uncommon; research shows that less than 5% of regular sexual partners will become infected (c.f. Department of Health (2004). *Hepatitis C: essential information for professionals and guidance on testing*. London: Department of Health/General Health Protection.

hepatitis C commenced) and alive at the end of August 2003. Payment is through the Skipton Fund (www.skiptonfund.org).

Chapter 2 outlines the Review methodology and participation rates.

Chapter 2

REVIEW METHODOLOGY

Introduction

In order to address implementation of the recommendations of the First Review, this Review involved interviews with all key stakeholders in blood product-related hepatitis C infection. Face-to-face interviews formed the main basis of information gathering for this Second Review (those consulted are listed in Appendix 2.1).

Tendering documentation for the Second Review included that some aspects of the first Review need not be repeated. Specifically, the random review of 25% of hospital patient charts was deemed unnecessary, as the National Disease Surveillance Centre was in the process of developing an ongoing database of clinical/medical chart information on all relevant hepatitis C patients. Secondly, rather than interviewing a random sample of patients with hepatitis C who would be contacted in a complex process through seven separate hospitals and consultants, it was decided that patient information could be accessed via the membership of the four patient support organisations (Positive Action, Transfusion Positive, the Irish Haemophilia Society and the Irish Kidney Association). This process was to be facilitated by the support organisations in the form of a brief postal questionnaire.

The methodology to address the areas of interest for the Review can be described as follows:

- information from those infected regarding satisfaction with aspects of their healthcare (including a detailed postal questionnaire and meetings with representative support organisations)
- information from the secondary care (hospital) units (interviews with unit staff)
- information from primary care services (interviews with Health Service Executive (former health board) personnel) and
- information from State institutions that have direct involvement with the hepatitis C issue. (interviews with key personnel).

The research protocol for the Second Review was given ethical approval by the Research Ethics Committee of the Royal College of Surgeons in Ireland [REC no. 94:3/8/2004].

The Review was conducted as follows:

1. Interviews with support organisations and membership surveys

The initial phase of the Review involved meeting with patient support organisations. Meetings with nominated representatives of the four patient support organisations – Positive Action, Transfusion Positive, the Irish Haemophilia Society and the Irish Kidney Association – were conducted in late Summer 2004. Interviews focused on the objectives of the Second Review - their views of progress in relation to the implementation of recommendations made in the first Review and any new healthcare

issues that may have arisen since completion of that Review. These interviews also formed the basis for planning the survey of their members. Consultation with the four patient support groups involved planning a common survey questionnaire that could be distributed by post to all hepatitis C relevant members of their groups. A draft questionnaire was developed by the Research Team following the initial set of support organisation interviews in Summer 2004. This was circulated to the four organisations for feedback and was refined further on this basis. An agreed questionnaire was prepared for distribution by all groups in early September (see Appendix 2.2). Each group was asked to circulate all relevant members with the questionnaire and a covering letter explaining the purpose and potential value to them of completing the questionnaire. (In the case of the Irish Haemophilia Society, a sub-set of members only was surveyed since another survey was planned by the Society in the same time period). Questionnaires were initially distributed in advance of an annual hepatitis C information day to be held in Dublin on September 18th 2004. The information day was taken as an opportunity for support organisations to encourage participation and emphasise the value to the Review of individual contributions on service experiences. The research team attended on the day to facilitate queries and/or survey replies from members of the support organisations. Reminder letters and forms were sent by support organisations in late September/October to maximize the survey response rate.

2. Interviews with hospital hepatology clinic staff

Staff at the seven centres designated as specialist adult hepatology units for this patient group were re-interviewed for the Second Review. The First Review did not consider specialist services for children infected with State-provided blood products. This centre was included in the Second Review. Interviews were held with consultant hepatologists in the seven adult units and with the designated consultant in the children's hospital. Other relevant clinic staff as determined by the local team were also interviewed on site: e.g. the hepatology nurse, clinic secretary and clinic counsellor. Interviews focused on the objectives of the Second Review, in particular recommendations from the First Review, which were most relevant to this group.

3. Interviews with Health Service Executive liaison officers

Each Health Service Executive has a designated liaison officer to manage hepatitis C services. Many of the recommendations of the first Review related to primary care service provision, an area that is coordinated largely by the Health Service Executive (former health board) liaison officer. Interviews were conducted across all 11 former health board areas with the relevant personnel. In some areas, deputy liaison officers also attended interviews and in the former Eastern Regional Health Authority (now the HSE Eastern Region), (the regional liaison officer was interviewed in addition to the three area liaison officers. Interviews focused on the objectives of the Second Review, in particular recommendations from the First Review, which were most relevant to this group.

4. Interviews with key State and national agencies

A number of key informants were consulted for the Review. These included staff at the Health Protection Surveillance Centre and the Blood Policy Division of the Department of Health and Children. The Consultative Council on Hepatitis C were also interviewed about their perception of implementation of the recommendations.

Survey response rate and demographic profile of participants

A total of 476 questionnaires were returned from the four support organisations; the majority (70%) were patients who had contracted hepatitis C from anti-D, followed by transfusion (25%), haemophilia (4%), and renal patients (1%). The majority were women (90%) and married (80%). Many (46%) worked in the home while others worked full-time outside the home (47% of the haemophilia, 18% of the anti-D and 20% of the transfusion groups respectively). The majority (61%) was infected in 1977 and about half diagnosed in 1994 (56%). Of participants, 98% had a Health Amendment Act (HAA) card. Regarding their overall self-rated health, four in ten described their health somewhat negatively (almost half (48%) said 'fair' and 12% 'poor'). The remainder (40%) described their health as 'good' or 'very good'. A significant 33% overall reported having a serious illness other than hepatitis C (with more of the transfusion than anti-D (35% vs. 26% respectively) reporting other serious illnesses).

The overall participation rate of those eligible was four in ten (39.9%) (476/1191). While this sample was not a random sample of the hepatitis C population, as was the case in the First Review, the majority of respondents reported having active hepatitis C. Thus, survey results are likely to represent views on services from those who use services most often.

Table 2.1 outlines some background information on the groups participating.

Table 2.1: Demographic profile of persons with hepatitis C as a result of State-contaminated blood supplies and participating in the survey

	ROUTE OF INFECTION				Total N=476 (response: 40%)
	Anti-D N=332/736 (response: 45%)	Haemophilia N=19/210 (response: 9%)	Renal N=3/25 (response: 12%)	Transfusion N=122/220 (response: 55%)	
Age-median (range) [years]	54 (25-70+)	45 (<25-59)	45 (<25-54)	58 (14-91)	54 (<25-70+)
Sex (% men) N (male:female)	(0%) 0:332	(89%) 17:2	(100%) 1:0	(25%) 30:92	(10%) 48:426
Number of children: median (range)	4 (0-11)	2 (0-5)	2 (0-2)	3 (0-10)	3 (0-11)
Distance (miles) from hospital, round trip - Median (range)	52 (0-300+)	70 (0-300+)	280 (150-299)	60 (0-300+)	60 (0-300+)

Half of the group were aged 54 years or above (median age), the vast majority were women (the largest group (anti-D) are by definition all women), half had 3 or more children and they lived an average 30 miles one way from their specialist hepatology unit.

It is important to note that the different sampling procedure used in this and the First Review means that some comparisons are made with caution or are not possible. In the First Review for instance, information on numbers of biopsies and other treatment came from hospital charts. In this situation they came from self-report. Where differences in sampling methods are important in interpreting results, they are highlighted. Because of the very small number of renal participants (N=3), it was not possible to draw statistical inferences from the information [as in the First Review]. Where all of those surveyed are described, information on this group is included. When separate support organisation information is provided, this group is not reported for the reasons just outlined.

Chapter 3 provides the main results of the Review.

Chapter 3

RESULTS I: Implementing Recommendations from the First Review

Progress on the 12 recommendations from the First Review is considered here. Evidence from all of the information sources is pooled to provide an overview of progress as perceived across constituencies. Additional information as obtained in consultation for the Second Review is included within the most appropriate section of the recommendations. At the end of this overview of progress on each recommendation, the recommendation is revised, if appropriate and is designated as a priority or a maintenance recommendation. Where a previous recommendation did not exist on an issue identified in this Second Review, this is now specified. Before considering information relating to recommendations, two issues need to be clarified. Firstly, it is important to consider the representativeness of the survey sample which informed a number of conclusions about progress on recommendations. The best way to do this with the information available is to consider the clinical status of the survey participants and compare it with that in the First Review.

Current clinical status

Data was available for 449 individuals, of whom 88% were women (Table 3.1). Twenty percent were PCR negative compared with 39% in the First Review, i.e., they showed evidence of acute hepatitis C without having developed chronic disease. Of the remainder, 9% were negative after treatment and 71% were PCR positive. It is important to note that PCR status and liver biopsy information was obtained from a chart review in the First Review and was the result of self-report for this Review. Since the likelihood of converting from PCR negative to positive is miniscule, the higher proportion of persons who were PCR negative in the First Review (where there was random selection from all hospital charts) suggests that those self-selected survey participants in the Second Review had more active hepatitis C than the overall group, i.e., were more ill. It is not surprising that those most engaged with their condition would be more likely to take part in a survey about services. The findings based on survey data must thus be viewed with some caution regarding generalisability.

Secondly, the survey response regarding satisfaction with services is included where appropriate within the chapter. A general point to note is the interpretation of satisfaction statistics. From a service provider's perspective, an 80% patient satisfaction rate could be considered acceptable; a patient advocate is more likely to focus on the 20% who are not satisfied in an effort to strive for change and continuous quality improvement. Both perspectives are legitimate and to be recommended to all constituencies – credit for work well done and commitment to continual quality improvement activity. Thus, rather than choose an arbitrary figure to define what constitutes 'satisfactory' services, it is more helpful to use the survey information as an aid in prioritising those areas of service meriting most attention.

Table 3.1: Evidence of disease status by route of infection and PCR status

PCR status by route of infection (N) Second Review (2004)	PCR status by route of infection (N) First Review (2000)	Number having liver biopsy in previous year (2004 data)	Number having liver biopsy (2000 data)
Anti-D	Anti-D	Anti-D	Anti-D
PCR positive (226)	PCR positive (164)		
PCR negative (69)	PCR negative (125)		
PCR negative after treatment (16)	Not available		
All anti-D		36 (12%)	194 (67%)
Haemophilia	Haemophilia	Haemophilia	Haemophilia
PCR positive (13)	PCR positive (14)		
PCR negative (4)	PCR negative (7)		
PCR negative after treatment (2)	Not available		
All haemophilia		1(9%)	5 (24%)
Transfusion	Transfusion	Transfusion	Transfusion
PCR positive (76)	PCR positive (57)		
PCR negative (19)	PCR negative (21)		
Negative after treatment (21)	Not available		
All transfusion		16 (15%)	44 (56%)
Total		53 (13%)	243 (63%)

The recommendations of the First Review are now considered sequentially.

RECOMMENDATION 1

THAT A COMMITTEE BE ESTABLISHED TO AGREE TREATMENT PROTOCOLS (INCLUDING LIVER BIOPSY PROCEDURES AND SCORING, AND ADMINISTRATION OF ANTI-VIRAL THERAPY) FOR THIS PARTICULAR GROUP. THE COMMITTEE SHOULD COMPRISE THE MEDICAL CONSULTANTS WITH PRIMARY RESPONSIBILITY FOR THIS GROUP OF PATIENTS AND BE CHAIRED ON A ROTATING BASIS.

A Sub-Committee of Medical Consultants was established following the First Review. The committee has met infrequently and has not formally convened for some time (although the relevant consultants meet regularly at national and international meetings). The Sub-Committee has agreed that the liver biopsy protocol in place in all hepatology units will conform to international recommendations as

published in GUT (1999). Guidelines relating to use of anti-viral (combination) therapy have been under review for some time but have not been formally approved by the Sub-Committee. Support organisations reported that members experience considerable differences across centres in the experience of anti-viral therapy and expressed a desire that standardised protocols be put in place nationally. Particular concerns were expressed because of the significant side effect profile of combination therapy for many recipients. This has been well documented internationally (e.g. increased depression and reduced quality of life (Zdilar et al, 2000; Hunt et al, 1997)). Some ambivalence was expressed in relation to the need for the Consultant Sub-Committee to meet regularly since it was felt that hepatology units adhere to international best practice guidelines. Drawing up new guidelines for the Irish context was seen to some extent to be “re-inventing the wheel”. The Consultative Council on Hepatitis C, however, have identified a need for ongoing expert advice in relation to a range of issues as they arise. An invitation was issued to the Chair of the Sub-Committee to this effect by the Tanaiste and Minister for Health and Children in November 2004. An example of an issue to be resolved for this hepatitis C group is that of management of hepatitis C in haemodialysis settings. This is a challenge, which overlaps with the business of other committees, for instance those concerned with infectious disease management in hospitals more generally. In this instance, as in relation to Recommendation 3 (on management of death more generally), the role of the Sub-Committee may be to expedite or inform the business of other groups in the interest of the Consultative Council’s work. For ongoing facilitation of relevant clinical issues, the Council would like to establish a more regular advisory link than currently (i.e., deliberations at least twice a year in future) from the Sub-Committee of Medical Consultants. This would facilitate Council planning and decision making. Support organisations were also of the view that consultants should meet two or more times a year.

In a separate development relating to recommendation 10, all hepatology consultants are members of the Scientific and Technical Group of the Hepatitis C Database at the Health Service Executive (HSE) – Health Protection Surveillance Centre (HPSC) (formally the National Disease Surveillance Centre). This Group has responsibility for agreeing the ongoing minimum dataset to be gathered for input to the national database. This process has worked well across a number of meetings and some consultant hepatologists have been available on an ongoing basis to advise HPSC staff on technical and scientific issues in this planning phase. In a further development concerning professional standards, the hepatology nurse specialist group has formally established an Irish Hepatology Nurses’ Association. This group has been meeting informally at the Irish Society of Gastroenterology (ISG) conference and is in the final stages of being established as a formal association. The group has and will continue to meet twice yearly. It aims to have an educational purpose, while also meeting to discuss issues arising in different units and to address standardisation of treatment and management across units. The chair of this association is to be rotated, possibly annually. These two developments highlight increasing opportunities for professional cooperation in this rapidly evolving clinical area.

Since Recommendation 1 was the one most broadly concerned with hospital aspects of quality of care, patient survey responses on satisfaction with these issues are presented here; specifically with specialist hepatitis C out-patient department (OPD) services; with general in-patient services; and with anti-viral (combination) therapy.

Satisfaction with specialist hepatitis C Outpatient Department (OPD) services

Participants were asked to rate their satisfaction with Hepatitis C outpatient services (i.e., the Hepatology Clinic). The majority was quite or very satisfied (78%). Of the remainder, 15% were neither satisfied nor dissatisfied, 6% were quite dissatisfied and 1% extremely dissatisfied. Satisfaction with outpatient services was similar across the support groups (Figure 3.1). Attendance at outpatient services ranged from 0-11+ visits in the previous year with the majority (91%) attending between 1-5 times (median: 2)(Table 3.2). The number of annual OPD visits either remained the same (49%) or decreased (37%) in the last five years. In the First Review the median number of OPD visits was also 2 (as noted by chart review). The transfusion and anti-D groups had similar attendance profiles at outpatient services; the haemophilia group had a significantly higher percentage recording “more visits than previously” to outpatient services (37% compared with 14% of the transfusion and 13% of the anti-D groups respectively). In general, patients were satisfied with the frequency of outpatient visits (84%), although 13% of the anti-D group and 14% of the transfusion group expressed a wish to attend more frequently. This is similar to the findings in the First Review, where interviews with patients revealed patient satisfaction with the frequency of OPD visits to be 87%.

Figure 3.1: Satisfaction with Hepatitis C Outpatients Department

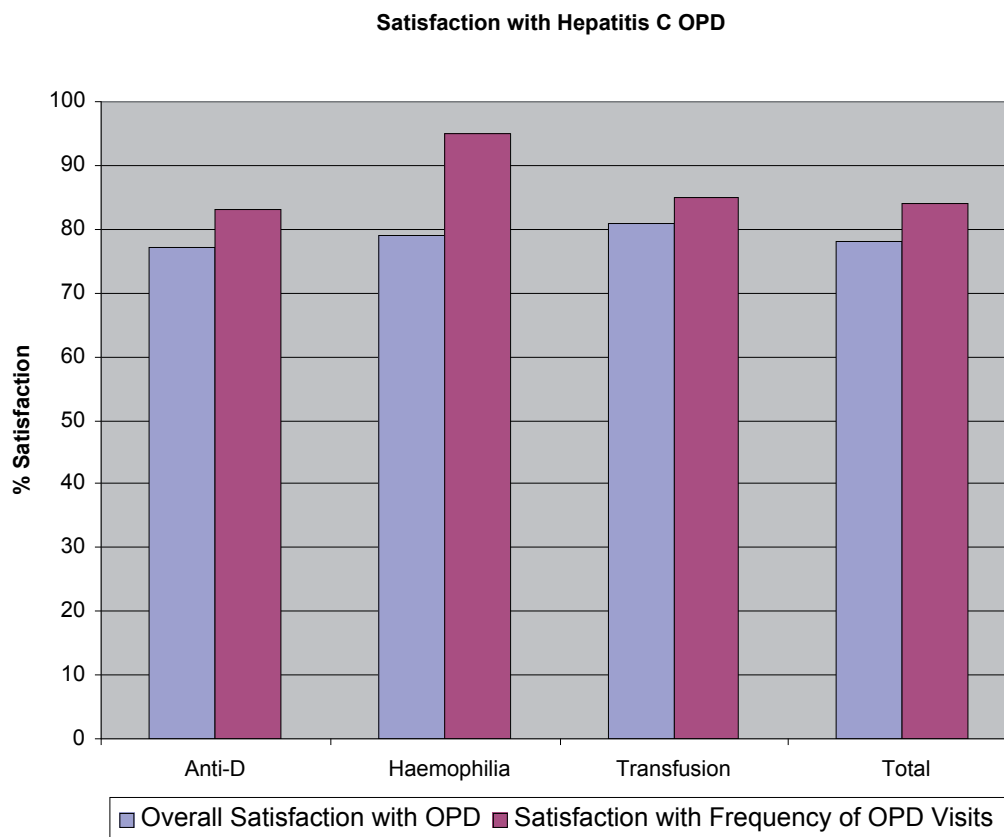


Table 3.2: Profile of patient attendance at Hepatitis C Outpatient Department (OPD)

	Anti-D	Haemophilia	Transfusion	Total
<i>Attendance at OPD; visits in previous year (range)</i>	0-11	1-11	0-11	0-11
<i>N=1-5 visits (%)</i>	92	88	85	91
<i>Mean number of visits</i>	2.5	3.4	3.9	2.9
<i>Median number of visits</i>	2	2	2	2
<i>Level of OPD visits same or less in the last 5 years: % :% (N)</i>	88 (314)	63 (19)	86 (109)	86 (445)

Satisfaction with the Hepatitis C OPD was measured further using 4 parameters: time spent with the doctor, thoroughness of care, respect for privacy and physical surroundings (Table 3.3). Satisfaction for time spent with the doctor was lower than for the other 3 aspects of care. Of participants, 70% rated this aspect of care as satisfactory compared with 88% for thoroughness of care and 90 % for respect for privacy. Satisfaction with time spent with the doctor was higher among the haemophilia (79%) and transfusion groups (76%) than the anti-D group (68%). Overall sample satisfaction with OPD physical surroundings was 80% but was significantly lower for the haemophilia group (47%). Specifically, of the haemophilia participants, 48% rated physical surroundings as fair or poor compared with 17% of the transfusion group and 18% of the anti-D group.

Table 3.3: Satisfaction with aspects of hepatitis C OPD services

	Anti-D % (N)	Haemophilia % (N)	Transfusion % (N)	Total % (N)
<i>Overall satisfaction*</i>	77 (323)	79 (19)	81 (119)	78 (464)
<i>Time spent with doctor</i>	68 (308)	79 (19)	76 (114)	70 (444)
<i>Thoroughness of care</i>	87 (311)	89 (19)	92 (112)	88 (445)
<i>Respect for privacy</i>	88 (311)	84 (19)	94 (114)	90 (447)
<i>Physical surroundings</i>	82 (312)	47 (19)	81 (114)	80 (448)

*Satisfaction: 'very good' or 'good' rating

Satisfaction about communication with hepatitis C staff at the OPD was generally satisfactory (Table 3.4). Overall satisfaction with the information given in the clinic, the opportunity to ask questions, explanations given about tests and procedures and

the opportunity to contact the clinic between appointments was high (scoring between 72-90%). Satisfaction was lower for the explanations about test results and clinical progress (72-77%). Twelve percent expressed dissatisfaction with explanations about test results and progress. Comparing satisfaction levels for aspects of care across the support groups, the haemophilia group reported higher satisfaction for all but one aspect of communication at the Hepatitis C clinic (i.e., opportunity to contact the clinic between appointments) (Table 3.4). Satisfaction with this aspect of communication was 61% for the haemophilia group (compared with 83% for the transfusion and 86% for the anti-D groups).

Table 3.4: Satisfaction with aspects of communication at the Hepatitis C OPD

	Anti-D % (N)	Haemophilia % (N)	Transfusion % (N)	Overall % (N)
<i>Information given at the clinic</i>	74 (311)	89 (19)	75 (113)	75 (446)
<i>Opportunity to ask questions at clinic</i>	80 (312)	90 (19)	78 (113)	80 (447)
<i>Explanations given about tests and procedures</i>	75 (309)	84 (19)	80 (113)	77 (444)
<i>Opportunity to contact clinic between appointments</i>	86 (305)	61 (18)	83 (110)	84 (436)
<i>Explanations given about test results & clinical progress</i>	70 (308)	84 (18)	73 (114)	72 (443)

* Satisfaction: 'extremely' and 'quite' satisfied results combined

Regarding travel to avail of health services, 18% reported difficulty travelling to hospital clinics. Of the remaining services, a minority reported difficulty travelling for counselling (9%), physiotherapy (9%), alternative therapies (9%) or other services (5%). Although 68% of participants overall felt they received the best quality of care in the previous year, satisfaction was lower for the haemophilia (58%) compared with anti-D (66%) and transfusion groups (73%). However, 37% of the haemophilia group reported not knowing whether they had received the best quality care with only 5% reporting they did not feel they had got the best quality care in the previous year (the latter compared with 16% of the anti-D and 15% of the transfusion groups). A minority changed hepatology units in the last year (4%). Almost all participants (94%) rated the quality of care in the hepatology unit they currently attend as the same or better than that in other hepatology units.

Satisfaction with general hospital in-patient services

Twenty-two per cent of participants reported being admitted to hospital in the previous year. Of these, 82% expressed satisfaction with their hospital stay. Comparing responses across support groups, the transfusion group was less satisfied with their hospital stay (62% expressing satisfaction compared with 89% of the anti-D and all (100%) of the haemophilia groups). Sixteen per cent of transfusion participants (n=5) expressed dissatisfaction with their hospital stay compared with 10% (n=4) of the anti-D group.

Satisfaction with anti-viral (combination) therapy

Anti-viral therapy was the focus of the survey question (rather than biopsy) as it was the issue causing most concern in the First Review and in early consultations for this Review with support organisations. The majority (82%) had not undergone combination therapy for Hepatitis C in the last year although 13% were planning to in the future. The majority (78%) of those who underwent treatment reported they were not given the opportunity to stay in hospital when combination therapy was initiated (Table 3.5). Of the 22% (n=4) who were given the opportunity to stay in hospital, length of stay ranged from 1-24 days, (mean 10.7, median 7) and was deemed adequate by all these patients. Half (50%) reported they were at least occasionally depressed while on combination therapy, with 31% often depressed and 13% depressed all of the time. Findings were broadly similar for the transfusion and anti-D groups. While on therapy, 76% were satisfied with the level of medical support available. Satisfaction was greater for the transfusion (85%) than the anti-D (67%) and haemophilia groups (75%). A third of the anti-D group expressed dissatisfaction with the level of medical support. No dissatisfaction was reported by transfusion or haemophilia patients undergoing therapy. Sixty-five percent were satisfied with the monitoring of side effects on therapy overall. Satisfaction was lower amongst the anti-D group where 50% were satisfied compared with 85% of the transfusion group. A third of the anti-D group expressed dissatisfaction with this aspect of care compared with only 14% of the transfusion and 25% of the haemophilia groups. Regarding counselling support while on therapy, satisfaction was poorer overall, with 56% of the patients satisfied. The haemophilia group was least satisfied with this aspect of service (25% expressing satisfaction compared with 60% of the anti-D and 71% of the transfusion participants). Overall satisfaction with combination therapy was 70%. Satisfaction with combination therapy overall was higher for the transfusion (85%) compared with anti-D (67%) and haemophilia (50%) groups. Of the anti-D group, 34% expressed dissatisfaction compared with none of the transfusion or haemophilia patients.

Table 3.5: Satisfaction with aspects of provision of combination therapy

	Anti-D % (N)	Haemophilia % (N)	Transfusion % (N)	Total % (N)
<i>Given opportunity to stay overnight</i>	14 (7)	0	43 (7)	22 (18)
<i>Length of hospital stay adequate</i>	100 (1)	NA	100 (3)	100 (4)
<i>Satisfaction with level of medical support</i>	67 (6)	75 (4)	85 (7)	76 (17)
<i>Satisfaction with monitoring of side effects</i>	50 (6)	50 (4)	85 (7)	65 (17)
<i>Satisfaction with level of counselling support</i>	60 (5)	25 (4)	71 (7)	56 (16)
<i>Overall satisfaction with combination therapy</i>	67 (6)	50 (4)	85 (7)	70 (17)

Information such as this, on patient perspectives of their care, need to be considered by the Consultative Council, and Medical Sub-Committee where appropriate, in particular where there is discrepancy between views of service providers and service users such as with anti-viral therapy.

Conclusion: the Consultative Council on Hepatitis C has identified a need for expert medical advice on issues that arise in the evolving management of hepatitis C. The Medical Consultant Sub-Committee is ideally placed to provide such advice on a specific issue or issues as identified by the Consultative Council. It is recommended therefore that the Medical Consultant Sub-Committee meet at least twice yearly to provide expert advice to the Consultative Council on issues identified by the Council. It is further recommended that the Consultative Council provide administrative support to the Sub-Committee.

Recommendation A (Recommend as a priority – Second Review)

That the Medical Consultant Sub-Committee meet at least twice yearly to provide expert advice to the Consultative Council on issues identified by the Council. It is further recommended that the Consultative Council provide administrative support to the Sub-Committee.

RECOMMENDATION 2

THAT THE SYSTEM WHEREBY PATIENTS ARE REFERRED BY THEIR CONSULTANT HEPATOLOGIST TO ANOTHER SPECIALTY BE REGULARISED TO FACILITATE HEPATOLOGY UNIT STAFF IN MAKING PRIORITY REFERRALS IN ACCORDANCE WITH THE 'TWO-WEEK' RULE. A COMPREHENSIVE REFERRAL SYSTEM FOR PHYSIOTHERAPY SHOULD BE ESTABLISHED TO ENSURE THAT IT IS AVAILABLE TO ALL WHO REQUIRE IT.

One of the provisions under the Health Amendment Act was a preferential appointment system for hepatitis C related referrals to medical specialists, providing for a first appointment within two weeks of the referral. This provision has come to be referred to as “the two-week rule”, and ensures a priority appointment within two weeks of referral for the first consultation, with subsequent appointments arranged on the basis of medical need. Perspectives on implementation of the two-week rule were very varied, both across patient support organizations and across hospital units. While one patient support organisation reported no complaints in relation to implementation of the two-week rule, others reported some units as much better at ensuring implementation of this rule than others. In some cases, patient support organisations felt they needed to make contact with specific hepatology units to ensure appointments were given within two weeks. In other cases, the success of the two-week rule was seen as due to personal contacts within the hospital, often among clinic secretarial staff. Rheumatology and dermatology were seen as particularly busy specialties and therefore among the most difficult in which to obtain appointments within the two-week timeframe.

Physiotherapy appointments had been singled out in the First Review as particularly difficult to obtain within the two-week timeframe. Physiotherapy appointments were no longer seen to be difficult to obtain. For those needing services, physiotherapy can now be obtained privately in the community and reimbursed through the health board (now Health Service Executive) liaison officer. This solution to a problem identified in the First Review appeared to work well for all concerned. Local physiotherapy access has meant that lengthy journeys to hospitals with specialist hepatology units for regular physiotherapy sessions are no longer required. Physiotherapy service use and acceptability was queried in the support organisation survey. A total of 151 participants (38%) availed of physiotherapy services in the year September 2003 – August 2004, 84 (21%) privately and 67 (17%) through the public system. Almost identical proportions of men (38%) and women (37%) attended. There were some differences by support group: 25 % of the anti-D group attended physiotherapy privately in comparison with 11% from the transfusion and none from the haemophilia group. Levels of satisfaction with the service were high at 88%.

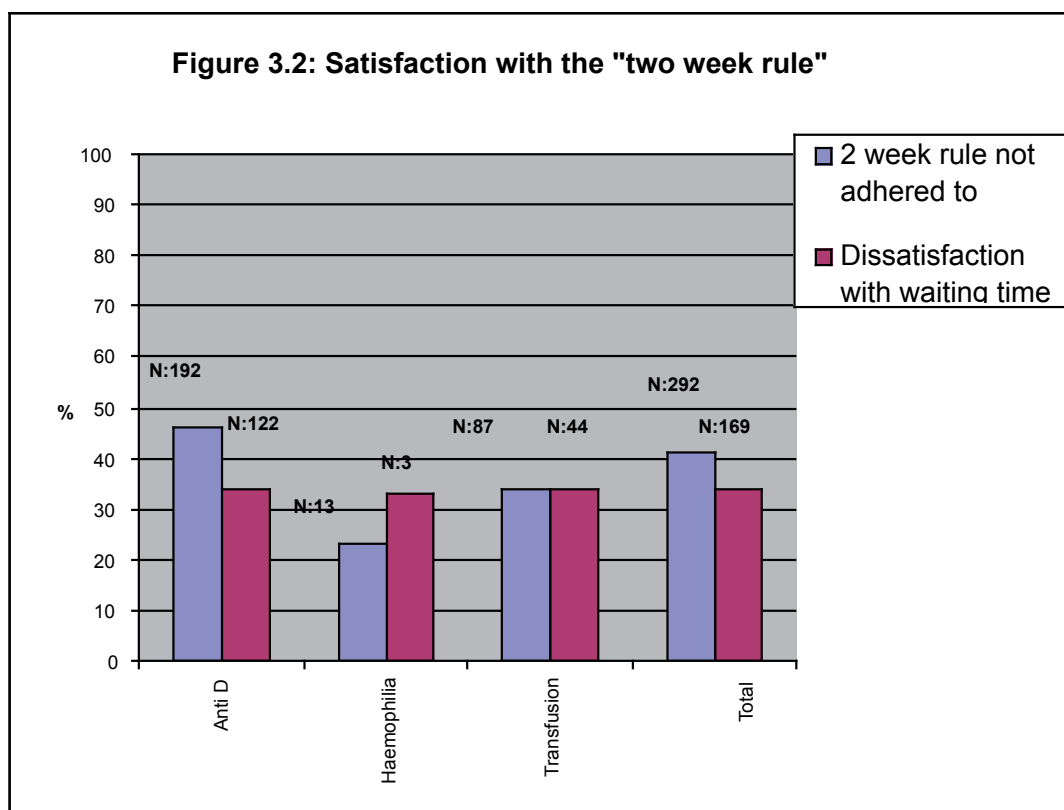
From the perspective of hepatology units, the two-week rule was, in general, seen to work well. However, the rule was considered problematic for a number of reasons. Where there is only one consultant in a specialty (for example, in rheumatology), it may not be possible to organize a two-week appointment if the consultant is away. The view from units was that patients were generally very understanding when this arose. However, the rule was described by some as “almost impossible” to implement in a busy hospital context.

As new consultants come into the health system and are unaware of the two-week rule, hepatology unit staff reported finding themselves in the position of constantly reiterating and re-negotiating the two-week entitlement across the hospital. Some hospital units have tried to address the issue with a standard referral letter template that explains HAA cardholder entitlements in the opening lines. One unit had tagged all relevant medical charts with a HAA cardholder stamp; other units felt that this was not a solution. The role of the Consultative Council in sending reminders to all hospital CEOs and consultants approximately every two years was considered important as a constant reminder of this very specific entitlement. This issue was considered one of increasing importance with the rising age profile of this specific population with hepatitis C.

The need for clarity in implementation of the two-week rule was emphasised. While the regulations stipulate use of the two-week rule for referrals that are hepatitis C related, determining whether or not a given referral is hepatitis C related has proven difficult in many situations. In some instances, professionals believed there could be misunderstanding among patients and/or support groups about the application of the two-week rule. The rule provides an entitlement to a first appointment within two weeks. Following this appointment, the patient is prioritised within the healthcare system according to medical need. This means a variable time may elapse before the next stage of treatment. Staff reported that some patients assume that the two-week rule applies to all further tests or appointments. Dealing with this misunderstanding was identified by unit staff as taking up a considerable amount of time within hepatology units. The two-week rule was further noted as applying to referrals from one hospital consultant to another. There was considerable confusion about the applicability of this rule to referrals made from a GP to a hospital doctor. In addition, some cases of referrals made by GPs to hospital specialists have been presented to hepatology units to pass on to, and arrange appointments from, the relevant specialty. The onus on the hepatology unit to ensure suitable and prompt first appointment dates and to negotiate patients' access to further appointments was identified as a considerable demand on staff time. It was felt that responsibility for arranging a two-week appointment for HAA cardholders should be with the specialty to which the referral was made rather than the hepatology unit.

In terms of evolving patterns of care delivery, it was noted that complaints in relation to implementation of the two-week rule no longer came to the Consultative Council or the Blood Policy Division of the Department of Health and Children. Where difficulties are experienced, it appears they are dealt with at local level, typically between representatives of the relevant support organisation and the hospital.

Patient perspectives on the two-week rule were examined in the survey. Regarding the two-week rule, 41% of those replying to this question (n=293) reported not being seen within two weeks of referral to other specialists or services within the last year; this comprised 46% anti-D, 34% transfusion and 23% haemophilia groups (Figure 3.2). Of those referred to specialists, 34% overall expressed dissatisfaction with the waiting time for referral with no virtually no differences across the support groups.



Conclusion: The implementation of the two-week rule continues to pose difficulties. These difficulties arise both from logistic and communication challenges within hospitals, and from misunderstandings about entitlements to the two-week rule. The specific problems with access to physiotherapy services have been resolved since publication of the First Review. It is recommended that the system whereby patients are referred by their consultant hepatologist to another specialty be regularly reviewed in each hospital so that hospital procedures facilitate Hepatology Unit staff in making priority referrals in accordance with the two-week rule.

Recommendation B (Recommend as a priority – Second Review)

That the system whereby patients are referred by their consultant hepatologist to another specialty be regularly reviewed in each hospital so that hospital procedures facilitate Hepatology Unit staff in making priority referrals in accordance with the two-week rule.

RECOMMENDATION 3

THAT GUIDELINES BE DEVELOPED FOR THE MANAGEMENT OF DEATH, INCLUDING FUNERAL ARRANGEMENTS, SO THAT THE NECESSARY SAFE PRACTICES ARE UNDERSTOOD AND ACCEPTED BY ALL CONCERNED.

Guidelines on the management of death have been under consideration by a number of groups for some time, but without clearly designated leadership. The Health Protection Surveillance Centre (HPSC) is to be formally invited, and has expressed willingness, to undertake a coordinating role in completing these guidelines. There are discrepancies in the manner in which death is managed in different regions nationally. Overall responsibility within each health board area for policy in relation to management of death lies with an infection control committee. However, in the majority of Health Service Executive Areas there are no written guidelines on management of death in the context of hepatitis C. In some hospitals, it is policy to use a 'body bag' where a patient is known to have had hepatitis C. The Health Service Executive – Southern Area (former Southern Health Board) recently adopted new policies in relation to management of death in the context of infectious disease. This policy no longer requires the use of body bags in the management of death of persons with hepatitis C. This policy also applies in some other hospitals, where death of a person with hepatitis C is managed in the same way as death of an individual who is not known to have an infectious condition. The rationale is that universal precautions are used in relation to management of all deaths, such that the same precautions need to be applied to all. When guidelines are completed, it was felt essential that the information included be disseminated in a thorough but sensitive manner. The information booklet format used for hepatitis C more generally was considered a very useful but not sufficient vehicle in communication of guidelines on this issue.

Conclusion: While considerable efforts have been made to develop national guidelines for the management of death, these have not been finalised. The Health Protection Surveillance Centre has agreed to coordinate their development. It is recommended that, as a matter of priority, guidelines for the management of death, including funeral arrangements, be agreed and widely disseminated so that the necessary safe practices are understood, accepted and used by all concerned.

Recommendation C (Recommend as a priority – Second Review)

That guidelines be developed for the management of death, including funeral arrangements, so that the necessary safe practices are understood, accepted and followed by all concerned.

RECOMMENDATION 4

THAT HEALTH BOARD LIAISON OFFICERS MEET ON A REGULAR BASIS TO ENSURE UNIFORMITY AND CONTINUITY IN THE PROVISION OF PRIMARY HEALTH CARE SERVICES.

The liaison officer role was identified in the First Review as one of the strengths of the system developed to support individuals with hepatitis C through State-provided blood products, liaison officers acting as a link between individual patients and their families, and what may be encountered as an unwieldy system. The need to co-ordinate and standardise health service delivery nationally was identified as a key issue in the First Review. It was recommended that the national liaison officer group meet on a regular basis to ensure this standardisation and uniformity of service provision. There are now quarterly meetings of the overall liaison officer group at the Department of Health and Children. These meetings commence with a meeting of liaison officers and the Blood Policy Division, followed by a meeting of the liaison officers and Blood Policy Division with support organisation representatives. These meetings monitor the consistency of service provision nationally and are deemed to be working very successfully by the liaison officer group. There are ongoing issues about standardisation of services to be addressed, e.g., optician services. Given the staff turnover of liaison officers nationally, the meetings were seen to be especially useful for new staff. Some emphasised the need for centrally formulated guidance about the role to be available to all, including newcomers to the job. One of the developments in the role of the liaison officer position since the First Review has been the designation of a deputy or assistant liaison officer in boards. This facility was developed to ensure that those contacting the service could more readily make contact with an informed and familiar liaison person. The number of service users in question is 1,422 (i.e., those with Health Amendment Act (HAA) cards). Breakdown of numbers across former health board areas is seen later in Tables 3.6 and 3.7.

Within the Health Service Executive (HSE) – Eastern Region (former Eastern Regional Health Authority), there were monthly meetings of the board liaison officers and the regional liaison officer. Local HSE liaison officers were also involved in the Hepatitis C Forum, which involves primary and secondary healthcare providers meeting with representatives of the four support organisations on a number of occasions each year. The meetings enabled local issues to be identified and dealt with at local level, while also ensuring streamlining of service provision across the HSE Eastern Region area. These meetings were deemed to work very well, alongside the national meetings held with the overall liaison officer group. They were considered effective in developing uniformity in dealing with issues as they arise. While this was acknowledged by all to work well, some discrepancies in service delivery across regions were still noted by support organisations. In the context of the restructuring of the health service (which occurred in January 2005 - shortly after the conclusion of consultation for this report), the Consultative Council envisaged that a national co-ordinator would be appointed with responsibility for this cohort. This person could address any ongoing differences across regions.

Conclusion: HSE liaison officers meet every 2-3 months with the Blood Policy Division of the Department of Health and Children and with patient support

organisations. The HSE Eastern Region convenes additional monthly meetings. These regular meetings have been found to be an effective means of ensuring standardisation of delivery of care nationally and as a means of identifying or anticipating issues as they arise. It is recommended, therefore, that liaison officers continue to meet on a regular basis to ensure ongoing uniformity and continuity in the provision of primary health care services.

Recommendation D (Recommend maintenance – Second Review)

That Health Service Executive liaison officers continue to meet on a regular basis to ensure ongoing uniformity and continuity in the provision of primary health care services.

RECOMMENDATION 5

THAT HEALTH BOARD LIAISON OFFICERS ENSURE CHOICE OF COUNSELLORS AND COUNSELLING LOCATIONS IN ALL HEALTH BOARD AREAS.

Inconsistent provision of counselling services was identified as a concern in the First Review, specifically in relation to choice of counsellors in some health board areas. This issue has been addressed, such that there is now a choice among a number of counsellors in all health board areas. The overall view was that there were adequate numbers of counsellors available in each health board area (Table 3.6). Over 170 counsellors are listed as available to provide services with 8.2% of service users registered with HSE liaison officers using services in the previous year. Note that counselling services are provided through HSE liaison officers but also through some of the support organisation counsellor staff and in hospital hepatology units. There appeared to be adequate numbers of, and several options for, availing of counselling for all needing it.

Despite efforts on the part of liaison officers, it has not been possible to recruit counsellors in a small number of specific locations. In some areas, those seeking counselling use a relatively small number of counsellors who are seen, by recommendation from other service users, as being most knowledgeable about hepatitis C issues. It was clear that counselling service users often made alternative arrangements when needing to represent their psychological status in the Compensation Tribunal. While this was acknowledged as less than ideal, it was also accepted that psychological representation in legal situations was a specialist role and that working with personnel other than one's own counsellor was important to best represent the person's status in a legal context. In some former health board areas (e.g., Southern Health Board, Eastern Regional Health Authority), specific training days have been held to inform and update counsellors on hepatitis C issues. The Mater Misericordiae University Hospital Dublin has also provided professional development support for counsellors working in hepatitis C. Counsellors in all areas must have recognised qualifications and registration with a professional organisation. The nature of the demand for counselling is becoming more specialised in some situations, e.g. marriage and bereavement counselling.

Table 3.6: Counselling service availability and use as funded through the former health board (now Health Service Executive) areas

	NAHB	SWAHB	ECAHB	ERHA Total	NEHB	NWHB	WHB	MWHB	SHB	SEHB	MHB	TOTAL
<i>Number of HAA card-holders in former health board*</i>	230	249	121	600	115	45	129	111	194	166	62	1422
<i>Number of counsellors available in former health board</i>	18	24	25	67	15	5	18	11	21	28	11	176
<i>Number of patients availing of counselling (%)</i>	11 (4.8)	11 (4.4)	8 (6.6)	30 (5)	6 (5%)	3 (6.6)	25 (19.4)	20 (9.9)	17 (8.8)	10 (6)	5 (8)	116 (8.2)
<i>Number of family members availing of counselling (%)</i>	5 (2.2)	2 (0.8)	5 (4.1)	12 (2)	4 (3.5)	2 (4)	2 (2.0)	5 (4.5)	2 (1)	2 (1)	0 (0)	29 (2)

*HAA cardholder numbers are a good approximation of the total number of persons with hepatitis C from State-infected blood in each health board (e.g. 98% of those surveyed were HAA cardholders). They are used here as numerators in calculating percentages of counsellors/counselling.

In terms of the psychological challenges of dealing with hepatitis C, participants in the support organisation survey were asked about stigma. Just over half of the participants (51%) felt they were stigmatised by their health condition. This compares with a figure of 37% from the First Review. With the caveat that sampling differed between the surveys, the percentage feeling stigmatised in the 2004 group represents a large proportion of those affected by this iatrogenic condition. The youngest group (those under age 44 years) had the highest proportion reporting stigma (57%) with the oldest group (those aged 65+) reporting the lowest levels of stigma (40%). While there were no gender differences across the relevant group comparisons in the survey, Transfusion Positive committee members highlighted the particular challenges relating to stigma and mis-information as experienced by men in their group. For much of the public, iatrogenic hepatitis C is seen as a women's issue and the largest group infected (those women receiving anti-D after childbirth) are recalled as the only ones who were infected though State-provided blood products. Thus men with iatrogenic infection reported finding that they were considered to be injecting drug users or to be homosexual.

Conclusion: Since the First Review, all health board liaison officers have identified a number of counsellors in their health board areas to enable people to attend counsellors in their locality, or at some distance from their locality, according to their wishes. This widespread availability of counsellors was considered a positive development by all constituents. It is recommended that health board liaison officers continue to ensure choice of counsellors and counselling locations in all health board areas.

Recommendation E (Recommend maintenance – Second Review)

That Health Service Executive liaison officers continue to ensure choice of counsellors and counselling locations in all health regions.

RECOMMENDATION 6

THAT A GENERAL TRAINING PROGRAMME FOR ALL HOME SUPPORT PROVIDERS BE AVAILABLE. THIS PROGRAMME MUST HAVE AS A BASIS AN AGREED STRATEGY REGARDING THE BALANCE TO BE ACHIEVED BETWEEN DUTY OF CARE TO THE PROVIDER AND THE RIGHT TO CONFIDENTIALITY OF HEALTH INFORMATION OF THE RECIPIENT.

In the context of State-acquired hepatitis C, many of those affected have designated their own home support provider. Table 3.7 outlines the present uptake of home support services across Health Service Executive Areas.

Provision of training for home support providers is available in almost all Health Service Executive Areas. In a small number of areas where all home support providers are nominated by the person with hepatitis C and there are no direct employees of the health board, there is no perceived need to provide training. In the majority of cases nationally, (almost 100% in some health board areas) home support providers are identified by those seeking home support, rather than being provided by a health board employee. A number of reasons were given for not wanting to avail of home support from a health board employee. These included the application of health and safety protocols derived from old age services that were considered inappropriate in the context of hepatitis C. Where training for home support is provided, it focuses on the use of universal precautions regarding the spread of infection. Home support providers recruited privately are free to attend training sessions in some Health Service Executive areas. However, where this is made available, there has been a very poor response to these courses, with few home support providers not directly employed by Health Service Executive areas attending. The primary reason given for non-attendance at courses is confidentiality, i.e., that home support providers are unaware of health board involvement in their employment or of the presence of hepatitis C in the home where they provide services.

Concerns were raised about the duty of care of persons with hepatitis C towards their home support provider where training has not been provided and, relatedly, the responsibility of Health Service Executive areas in this regard. The risk of hepatitis C infection to the home support provider and subsequent possible financial liability and other responsibility (of both the original person with hepatitis C and the health board) was raised as an unlikely but possible scenario. Issues concerning employer status in relation to home support providers were also raised.

**Table 3.7: Home support service uptake and hours used per week
across the former health board
(now Health Service Executive) areas**

	NAHB	SWAHB	ECAHB	ERHA Total	NEHB	NWHB	WHB	MWHB	SHB	SEHB	MHB	TOTAL
<i>Number of HAA card-holders in former health board</i>	230	249	121	600	115	45	129	111	194	166	62	1422
<i>Number of cardholders with home support 2004 (%)</i>	79 (34)	95 (38)	45 (37)	219 (37)	36 (31)	19 (42)	44 (34)	51 (46)	88 (45)	65 (39)	11 (18)	533 (37.5)
<i>Percentage of card-holders with home support 1997/8</i>	N/A	N/A	N/A	20.1	12.4	30.3	18.2	41.0	37.4	27.2	15.1	25.2
<i>Average number of hours per week (2004)</i>	14	13	13.7	13.6	15.9	11.0	15.75	19.4	15.6	15.7	15.0	15.1
<i>Average number of hours per week (1997/8)</i>	N/A	N/A	N/A	6.2	9.2	12.2	10.0	13.2	12.0	11.4	9.0	10.4
<i>Number with 0-10 hours per week</i>	34	57	21	112	11	13	11	9	22	19	5	202
<i>Number with 11-20 hours per week</i>	40	33	19	92	19	4	21	29	61	36	4	266
<i>Number with 21-30 hours per week</i>	4	1	4	9	5	2	7	10	3	7	1	44
<i>Number with 30+ hours per week</i>	1	4	1	6	1	0	5	3	2	3	1	21

In addition, concerns were expressed regarding the added strain that would be placed on a family member who, in addition to their primary supportive role was also acting in a home support role, if the patient's condition deteriorated. Some health boards have written to those using self-selected home support emphasising the responsibilities of the person with hepatitis C as an employer. Where the Health Service Executive is the employer, the need to provide health & safety guidance for employees has been interpreted by Health Service Executive Areas as requiring that the hepatitis C status of the service recipient should be disclosed.

From the perspective of service users, 64%² of those surveyed had used home support services in the year September 2003 to August 2004. Of these, 26% were provided and paid for directly by the then health board, while the remaining 36% sourced and paid for home support privately and were reimbursed by the health board. Women were much more likely to use home support than men (67% versus 35%), while those under age 44 were least likely to avail of it (41% versus 67% for those aged 45-54, 84% for those aged 55-64, and 45% for those aged 65+). The transfusion group were more likely to use home support provided and paid for by the health board (48%), while anti-D group members were more likely to source their own home support (64%). The average number of hours of home support used by those availing of services was 13.6 hours per week. The most common use was 6-10 hours (used by 35%), followed by 11-15 hours (26%) and 16-20 hours (23%). Five per cent used 21-30 hours, while 2% used 31 hours or more. There was very high satisfaction with the home help service (44% satisfied or very satisfied).

In terms of the complexity of employer and responsibility relationships in this area, findings of a separate and informative survey, as undertaken by Positive Action in early 2004, is noted here. They circulated their (anti-D route of infection) members about home support and had 387 replies, of which 267 (69%) were using home support services. Of these, 73% said their home support worker was aware of their diagnosis. In terms of payment, 77% paid for the service themselves and were reimbursed by the then health boards. Of the 60 people paid by health boards for home support services, it was reported that 48 had been identified by the Positive Action member herself and then employed by the health board. Home support staff identified by service users were reported as being employed by six of the 11 former health boards according to the Positive Action survey. These findings question the view expressed of some health professionals - that all self-selected home support staff are the responsibility of the service user rather than the health board – and further highlight the need for clarity in this area.

Conclusions relating to recommendation 6 are taken in conjunction with the related recommendation 7.

² Note: As with clinical status parameters outlined in Table 6, 64% is higher than the 38% overall population use as noted by the liaison officers (Table 3.7). Hours used per week also differ somewhat. This is further evidence that survey responders are higher service users than non-responders.

RECOMMENDATION 7

THAT THE ISSUES SURROUNDING THE DIFFICULTY IN RECRUITMENT OF HOME SUPPORT PROVIDERS, INCLUDING REMUNERATION ISSUES, BE REVIEWED TO ENSURE AVAILABILITY OF THE SERVICE TO ALL WHO REQUIRE IT.

None of the Health Service Executive Areas reported experiencing difficulties with recruitment of home support providers, primarily because providers were being sourced by persons with hepatitis C themselves. The issue of remuneration has been standardised nationally since the First Review to a common rate across regions of €10 - €11. However, serious concerns were raised about payment of home support and the overall cost of home support services. Home support is provided by health board (now Health Service Executive area) liaison officers in response to a letter of request from the GP or consultant hepatologist of the person with hepatitis C. Assessment of need by a public health nurse is not required for eligibility as it is in other aspects of the health system. In most cases nationally, home support providers are paid directly by HAA cardholders and the cost is recouped by a grant from the health board. In most health board (now Health Service Executive) areas, rate of payment for home support is increased in accordance with national wage agreements, but payment is not incremental. Nationally, 38% of those with State-linked hepatitis C currently avail of home support services (this compares, for instance, with figures of 5% for those in the general population aged over 65 years availing of home support in 2004 in the Western Health Board and 9% in the ERHA region (O'Hanlon et al., 2005)). Comparisons with the First Review (data refer to 1997/8) of the percentage of people with hepatitis C availing of home support in and with the average number of hours availed of per week show an increase in both the percentage availing of home support and in the time availed of per week (Table 3.7). In some regions, the cost of home support is estimated as two-thirds of the annual State-infection related hepatitis C budget. Issues of transparency and accountability of monies provided in grants to patients to pay home support salaries directly were seen as a source of fiscal vulnerability and concern on the part of Health Service Executive Areas. The development of a position paper on the overall provision of home support services was acknowledged by a number of liaison officers and a desire expressed that difficult issues in relation to this service be resolved in the near future.

While there were concerns about aspects of home support services, a number of positive features of the recruitment status as it has evolved with the particular concerns for confidentiality of this hepatitis C group were noted. In the current situation of employment embargos in the public service, it would have been very difficult to increase home support staff employees of the Health Service Executive Areas in recent years. The model of self-selection of home supports has been piloted elsewhere as a consequence of its evolution in the context of hepatitis C. For instance, it has been used in a pilot early hospital patient discharge scheme for older people in Beaumont Hospital, Dublin. It can form part of a series of resources to support safe early discharge from hospital.

Conclusion (recommendations 6 and 7): Standardisation of salary payments of home support providers across the country has been resolved since the First Review. However, there are significant ongoing difficulties in relation to this service. In the majority of cases nationally, persons with hepatitis C select their own home support provider and recoup payments from the Health Service Executive area. It is unclear who has employer responsibility including liability. The lack of transparency and accountability, and the vulnerability of all concerned (home support recipients and providers and Health Service Executive areas), was identified as a significant source of concern. Ongoing efforts are being made by the Consultative Council, liaison officers and patient support organisations to resolve these difficulties. It is recommended that the position of home support provider be regularised with due regard for patient confidentiality, while also ensuring statutory legal requirements in relation to employment are fulfilled. Given the importance of this area, and the differing perspectives on responsibility, the Consultative Council has requested that the Department of Health and Children seek legal advice on the issue.

Recommendation F (Recommend as a priority – Second Review)

That the position of home support provider be regularised with due regard for patient confidentiality, while also ensuring statutory legal requirements in relation to employment are fulfilled.

RECOMMENDATION 8

THAT STAFF IN ALL PRIMARY CARE DISCIPLINES DEALING WITH THIS PATIENT GROUP (INCLUDING GENERAL PRACTITIONERS, DENTISTS AND PHARMACISTS) BE ADEQUATELY INFORMED ABOUT THE ACTUAL RISK OF TRANSMISSION OF HEPATITIS C AND THE GUIDELINES ON UNIVERSAL PRECAUTIONS AGAINST TRANSMISSION OF INFECTION; THIS IS TO ENSURE THAT SUCH PATIENTS ARE TREATED IN A SENSITIVE MANNER. RESPONSIBILITY FOR REGULAR TRAINING UPDATES SHOULD BE WITH THE LIAISON OFFICERS WITH RESPONSIBLE ONSITE STAFF ENSURING ADEQUATE BRIEFINGS FOR NEW STAFF BETWEEN TRAINING UPDATES.

Health professionals in the primary care setting are provided with information on universal precautions. In the first instance, an information guide detailing entitlements of HAA cardholders has been circulated to all service providers by the Department of Health and Children. These providers included liaison officers, primary care managers, general managers and heads of health professional disciplines. The guide has been found to be very useful and has enabled most queries to be dealt with without difficulty. Where problems have arisen in the primary care setting, health professionals (e.g., dentists, GPs, opticians, pharmacists) have been advised to contact the liaison officer immediately. When problems have arisen, it has often been because each primary care service provider has had to deal with very few HAA cardholders and/or high levels of staff turnover resulting in staff unfamiliarity with entitlements. The fact that the HAA card is blue (the colour of the old medical card) may also cause some confusion among some primary care providers. All documentation distributed by the Consultative Council on Hepatitis C now has a corporate logo (orange sunflower) to enable easy recognition of its publications. In addition, the HAA card is

now being distributed as a swipe card, so that all entitlements will be visible to the primary health care provider when the card is swiped. Distribution of this swipe card is ongoing.

The second aspect of informing professionals involves the liaison officers. Regular reminders and updates about services are distributed by the liaison officers to primary health care providers to ensure that frontline staff are adequately trained on an ongoing basis. This system has been seen as broadly successful in maintaining awareness of hepatitis C related entitlements amongst primary health care professionals. However, a significant proportion of service users surveyed for the Second Review still report dissatisfaction with primary care professional awareness of services as discussed later and outlined in figures 3.3 and 3.4. An ongoing challenge to maintain adequately informed staff is the relative infrequency of information queries concerning hepatitis C and staff turnover in the health system. It must be the responsibility of senior staff on site in primary healthcare settings to ensure the education of new staff. Increasing the use of information technology may improve staff awareness of service entitlements, e.g., in the pharmacy setting.

Conclusion: Training of all front line primary care staff on the importance of universal precautions is reviewed on a regular basis, with resulting increased levels of awareness among staff. The availability of an Information Guide detailing entitlements under the HAA has been found to be very useful. The ability of primary care providers to contact the liaison officer should any difficulties arise has also helped ensure quality service provision. It is recommended that staff in all primary care disciplines dealing with this patient group (including general practitioners, dentists and pharmacists) continue to be adequately informed about the actual risk of transmission of hepatitis C and the guidelines on universal precautions against transmission of infection; this is to ensure that such patients are treated in a sensitive manner. It is further recommended that primary care service providers continue to be made aware of the potential to contact the health board liaison officer, if necessary. In terms of accountability, there is a cascade of responsibility from the Consultative Council (with responsibility for updating clinical and service entitlement information in written form) to the liaison officers (with responsibility for updating primary healthcare professionals on a regular basis) to senior primary healthcare professionals (with interim responsibility for ensuring training of new staff between briefings by liaison officers).

Recommendation G (Recommend maintenance – Second Review)

That staff in all primary care disciplines dealing with this patient group (including general practitioners, dentists and pharmacists) continue to be adequately informed about the actual risk of transmission of hepatitis C and the guidelines on universal precautions against transmission of infection; this is to ensure that such patients are treated in a sensitive manner. It is further recommended that primary care service providers continue to be made aware of the potential to contact the Health Service Executive liaison officer, if necessary.

RECOMMENDATION 9

THAT THE ROLE OF COMPLEMENTARY OR ALTERNATIVE THERAPIES IN THE MANAGEMENT OF HEPATITIS C BE REVIEWED AS PART OF A WIDER FRAMEWORK OF EVALUATION OF THE USE OF SUCH THERAPIES IN THE IRISH HEALTH SYSTEM.

The use of complementary therapies by adults with hepatitis C was reported to have increased significantly in the last 6-12 months. The expectation is that demand for these services will continue to increase steadily. There was little demand for complementary therapies for children and adolescents with hepatitis C. The complementary therapies in greatest demand were massage, aromatherapy and reflexology. These therapies are provided in a small number of the hepatology units. However, most units do not provide complementary therapies on site. Positive Action employ two nurses part-time and Transfusion Positive employ one nurse, all of whom are trained in complementary therapies. Members can attend these therapists at the support organisation offices. Payment at support organisations is directly to the therapist, with reimbursement from the Health Service Executive. Use of herbal remedies is not funded through the Health Service Executive unless a letter is provided by the individual's consultant hepatologist or GP and is provided by a qualified, registered practitioner. Reimbursement from the Health Service Executive is only provided if the therapist is a registered health professional, for example, doctor, nurse, or physiotherapist. Concern was expressed about this limitation, as it can be difficult to identify an accessible complementary therapist in some, especially rural, areas. Where professional organisations exist for some complementary therapies, they may be unwilling to provide selected lists of members identifying those with Government recognised health professional qualifications since a selected list can discriminate against some of their members. Support organisations reported significant numbers of their membership who would like to avail of complementary therapies, but were unable to due to unavailability of therapists. The need to regularise alternative therapies was identified as a matter of urgency. A registering body for complementary therapists to enable health professionals to identify suitably qualified personnel was proposed. The Department of Health and Children had advised the Consultative Council that a National Working Group on the Regulation of Complementary Therapists was established to examine this area. The Department had also provided information concerning an EU Directive on herbal medicines, which allows for the establishment of a committee to evaluate medicinal products. The current status is that no complementary therapy is regulated by the Department of Health and Children or by any recognised regulatory agency acting on its behalf. Neither are there any statutory registration bodies for those offering such services in Ireland. Given this status, some members of the Consultative Council were of the view that the Review's recommendation had been implemented as far as was allowable given the current role of complementary medicine within the health service. A support organisation view was that no progress had been made on the issue since the last Review because of the more general inertia on the issue.

The support organisation survey found that 138 (39%) of participants used complementary therapies in the year September 2003 – August 2004. A higher proportion of the anti-D group used complementary therapies (43% compared with 32% of the transfusion group). Participants reported using a wide range of therapies.

The most popular was reflexology, used by 66%, followed by massage (58%), aromatherapy (29%), chiropody (26%), special diets (11%), homeopathy (10%) and other therapies (12%). A higher proportion of women than men used these therapies (30% vs. 19% respectively). A higher proportion of men used reflexology (78% compared to 65% women), while a higher proportion of women used aromatherapy and chiropody (30% versus 22% men and 28% versus 11% men respectively). No men used special diets or homeopathy, while 11% of women used both. There was a very high level of satisfaction (90%) with complementary therapies.

However, survey findings also indicated ongoing difficulties for many individuals in accessing complementary therapies. At the time of the First Review, many patients reported difficulty with access to complementary therapies. Findings from this survey indicate that this issues still remains, with 53% reporting difficulties. Furthermore, at the end of the survey instrument, participants were asked in an open-ended question to indicate if there were any services they would like to have used in the previous year but had not done so (and reasons for this where relevant). Many (118 of 476: 25%) chose to indicate services needed but not used. The main service needed but not used was complementary therapy. Over one in three of those indicating they needed a service listed complementary therapy with most saying either they could not afford the therapy (indicating some confusion about reimbursement), they could not afford to pay and wait for reimbursement by the health board, or they could not access services (not knowing where they were or being too far away from relevant services). In the First Review, there were some difficulties in being reimbursed for complementary therapies. In this survey, just over half (52%) reported prompt reimbursement, while a quarter (23%) had to wait for more than a month for repayment. One in eight (13%) paid for therapy but were not reimbursed while 14 (11%) did not have to pay (either where services were provided by public system staff or where the professional involved billed the health board directly). A higher proportion of anti-D group members reported prompt payment (55% versus 46% for the transfusion group; no direct payments by other groups).

Conclusion: A recent significant increase in demand for complementary therapies was reported, with an expectation that this demand will continue to increase even further. The requirement that complementary therapists have another health professional qualification has been found to be restrictive, particularly in rural areas. It has created difficulties also in obtaining lists from registration bodies for complementary therapies. It is recommended, as in the First Review, that the role of complementary therapies in the management of hepatitis C be reviewed as part of a wider framework of evaluation of the use of such therapies in the Irish health system. Those involved in hepatitis C services need to advocate for the wider structures within which their specific concerns can be met as there appears to be little progress in regulation of complementary therapy professionals in the past five years, while the use of such services has expanded significantly, in hepatitis C services as elsewhere.

Recommendation H (Recommend as a priority – Second Review)

That a review of the role of complementary or alternative therapies in the management of hepatitis C be advocated for as part of a wider framework of evaluation of the use of such therapies in the Irish health system.

RECOMMENDATION 10

That a national database be established for research purposes; this to be located at an independent coordinating agency and run in association with relevant groupings.

The Health Protection Surveillance Centre (HPSC) (formerly National Disease Surveillance Centre (NDSC)) has been identified as the national centre to develop this database. From mid-2004 the database has been in development in conjunction with the eight designated hepatology units nationally. The procedure is that each person infected (or parents of those aged less than 18 years) is invited, by letter and information leaflet by their hepatology consultant, to agree to have their information stored on the HPSC database. Written consent is to be obtained by postal return of consent forms to the hepatology unit. Where this is provided, information will be forwarded from the unit approximately once annually to the HPSC. Names and addresses will not be transferred; date of birth and initials will be used in order to have a unique identifier for ongoing data collection and to ensure that there are no duplicate files (e.g., where a person has attended more than one unit over time). A Hepatitis C Database Steering Committee will manage the database. Its membership includes representatives from patient support organisations, consultant hepatologists, hepatology nurses, health board liaison officers, counsellors, directors of public health and the Department of Health and Children. A Scientific and Technical Group supports their work. Membership of this Group comprises all of the hepatology consultants, a hepatology nurse, a haematologist (representative of the Irish Haematology Society)³, representatives of the patient support organisations and a biomedical research specialist in hepatitis C. Access to information will be approved by the Steering Committee. Information sought for patient registration is in five sections: patient demographic and hepatitis C background details; clinical status (including liver and non-liver manifestations of hepatitis C infection); clinical management details (e.g., tests undertaken and appointments attended); hepatitis C related test results (e.g., PCR, liver function and genotype); and treatment (e.g., anti-viral medication, complementary therapy).

In the first instance, registration information retrieval is being undertaken by an experienced research nurse employed centrally by HPSC and visiting each centre to extract data. When this initial task is complete, it is envisaged this nurse will have a training, standards and coordination role. In subsequent years, each centre will provide the necessary information on an annual basis to update the database. Recruitment of patients to the database commenced in mid-2004. Reminder letters were sent by consultant hepatologists to those not responding some months later. By December 2004, almost 70% of affected patients had given permission for inclusion on the database. Two percent formally wrote to withhold permission. The role of patient support organisations in promoting participation was credited by the HPSC. A clear protocol for joint ownership of the database information was also useful in achieving cooperation across the agencies concerned. The success of database recruitment at this early point is encouraging. Ongoing promotion by the HPSC, hepatology units and support organizations can increase this participation rate in the future. Feedback of information from the database through support organization

³ At the time of the consultation (December 2004), there was no Irish Haematology Society representative on the Scientific and Technical Group.

communications (newsletters, information days, etc.) can demonstrate the communal value of the database.

The medical chart information retrieval task is underway since December 2004. For three hospitals, most but not all of the information can be retrieved by extraction from a dedicated hospital information system. While the research nurse employed to conduct this exercise nationally is appointed for six months in the first instance, this post is seen as one requiring considerable expertise and one which should continue if complete and high quality information is to be collected regularly and efficiently from hepatology units over the coming years.

Challenges for the future of the database are to increase participation above 70% and to select clinically and biologically meaningful comparison samples for research (in some instances comparison with those groups which are most useful from a research perspective may be socially sensitive, e.g., comparisons with injecting drug users). As in other areas, assurance of ongoing funding is an issue. To date all funds needed to establish the database have been forthcoming. However, the issue of staff retention will arise quite soon in the context of an experienced research nurse to promote and maintain the database. With their broad brief of disease surveillance for the overall population, the HPSC foresee the growing number of non-State infected hepatitis C patients as a particularly challenging public health issue for the future.

Other activities since the First Review indicate the commitment of all concerned to hepatitis C research and an evidence base for actions in this area. In June 2003, the previous Consultative Council on Hepatitis C hosted an international conference in Trinity College Dublin. Entitled *Hepatitis C: - past, present and future*, the conference had an academic programme where the latest scientific research could be presented and discussed alongside a translational programme where the meaning of research findings for policy makers, practitioners and those living with the condition was considered. Also in 2003, the Health Research Board announced a separate and additional research budget allocation from the Department of Health and Children for hepatitis C. A substantial research programme and three smaller project grants were awarded (total investment of €1,036,743). The research themes funded were:

- Characterisation of hepatitis C induced immunological subversion and its implications for treatment response [Principal Investigator: Professor Cliona O'Farrelly, St Vincent's University Hospital, Dublin]
- Establishing a model of care utilizing non-invasive markers of disease progression and treatment outcomes in differing cohorts of HCV-infected persons [Principal Investigator: Dr. Suzanne Norris, St James's Hospital, Dublin]
- Efficient in vitro replication of HCV: is it a question of the right cytokine environment? [Principal Investigator: Dr. Liam Fanning, Cork University Hospital]
- Molecular analysis and virological basis of response to therapy of two populations of Irish women infected with HCV genotypes 1b or 3a through contaminated anti-D products [Principal Investigator: Dr. Margaret Duffy, University College Dublin].

The projects outlined above were biomedically focussed projects. A number of separate research teams in Dublin and Cork have also conducted and published

funded work in the international research literature on psychosocial aspects of hepatitis C (e.g. Coughlan et al., 2002; Dunne et al., 2002 and Hickey et al., 2003). Support organisations have also undertaken focused research surveys with significant support from members. For instance, Positive Action surveyed members on their use of home support services early in 2004 (some information from this survey was presented earlier). Overall there has been considerable progress on research issues concerning hepatitis C since the First Review.

Conclusion: The Health Protection Surveillance Centre is at an advanced stage of establishing a national hepatitis C database. All hepatology units contacted in writing their patient listing in the latter half of 2004 informing patients of the database and requesting their consent for recording of their clinical data. It is recommended that this national database be maintained for research purposes; this to continue to be located at an independent coordinating agency and run in association with relevant groupings. Promotion of the value of the database should be ongoing to maintain those already providing data and to increase patient participation even further.

Recommendation I (Recommend maintenance – Second Review)

That the national database be maintained for research purposes; this to continue to be located at an independent coordinating agency; to be run in association with relevant groupings; and to work with others to maintain and increase database coverage of the relevant population.

RECOMMENDATION 11

THAT ASSURANCES BE GIVEN THAT ADEQUATE FUNDING AND RESOURCES WILL CONTINUE TO BE PROVIDED TO ENSURE A QUALITY HEALTH CARE SERVICE FOR THIS PATIENT GROUP.

The overall consensus amongst healthcare providers is that adequate funding and resources continue to be provided and that this funding is sufficiently ‘ring-fenced’ that there are no great concerns that adequate levels of funding will not continue into the future. Some noted that services were committed to in law and, as such, the funding for these services was protected. However, a number of hepatology units, particularly those based in Dublin, identified evolving difficulties with staffing, both nursing and medical, in a context of an ageing hepatitis C population and greatly increasing numbers of other hepatitis patients (hepatitis C, but more particularly hepatitis B) who also attend these units. The former health boards (now Health Service Executive areas) provided quarterly expense returns to the Blood Policy Division of the Department of Health and Children, so that the costs incurred in each area were clear as the financial year progressed (This was the health board reporting situation that pertained in 2004 - at the time of conducting this review. Plans for reporting through the new Health Service Executive were not discussed). Within these former health boards, the budget was reviewed at 3, 6 and 9 months. At the 9 month review it was apparent, typically, if supplementary funding would be required. Where additional funding was needed, monies available in other areas within the board could be transferred for hepatitis C services. Where this was not possible, a supplement was requested from the Department of Health and Children and this was always provided.

However, concerns were raised about the likely significant increase in costs and budgetary requirements as the population with hepatitis C become older and the need for service provision increases. For instance, in each region, the proportion of persons with hepatitis C availing of home support services was less than 50%. The demand for this service has increased by 12.3% since the First Review and is likely to continue to increase considerably. The need for home nursing has not been a substantial demand up to now, but is anticipated to increase considerably in the medium to long-term also. The demand-led nature of the service was also highlighted as problematic in budget terms. For example, a once-off request for a large item, such as a special bed, may have taken 10% of the annual hepatitis C budget of a particular health board. Support organisations were less confident about adequacy of funding and resourcing of services. They sense 'slippage' in some areas and feel the need to monitor service provision more closely now than before. Concerns relating to funding include less frequent hospital clinic appointments, a perceived lack of accountability in relation to spending in some hospitals, increased bureaucracy to access entitlements under the HAA (with former health board staff seen to question provision of services for which there is an entitlement). At the level of resources for individuals with hepatitis C, many of the services to which they are entitled can or need to be accessed on a payment and later health board reimbursement basis. Difficulties have been reported because of delay in being reimbursed for fees paid. As fees for frequent service use can add up to substantial amounts of money, some have reported not availing of services because reimbursement can take up to 6-7 weeks, in some cases.

On a wider level, the influence of new health service structures including the Health Service Executive (HSE) from January 2005 means that the systems, which have been in place, will change significantly in the coming years. Successive governments have assured the Consultative Council on Hepatitis C and the four support organisations that funding for services will continue to be ring-fenced. The HSE will have responsibility for ensuring that the funding provided by the Department of Health and Children is best targeted to provide the necessary levels and quality of service. Under the Health Act 2004, all health funding will be channelled through the HSE. The Chief Executive Officer of the HSE will have legal responsibility for delivering the services in the Health (Amendment) Act 1996. A further key function of the HSE will be to make the case to the Department of Health and Children, as part of the annual estimates process, for a greater level of funding where this is required in the future. Nonetheless, there needs to be ongoing overview to ensure that funding, as well as other aspects of service delivery, which have been evolving since 1994, do not disimprove.

Conclusion: Overall, the ongoing provision of funding is not a source of major concern. Nonetheless, at an individual level, delays in reimbursement can be problematic. While budgets may over-run in a given year, requests to the Department of Health and Children for supplementary funding have been facilitated. However, it is anticipated that there will be considerable increases in costs associated with provision of some services in the short to medium term, in particular home support and complementary therapies. It is recommended, therefore, that continuing assurances be given by the new health service agencies that adequate funding and resources will be provided to ensure a quality health care service for this patient group.

Recommendation J (Recommend maintenance – Second Review)

That continuing assurances be given that adequate funding and resources will be provided to ensure a quality health care service for this patient group.

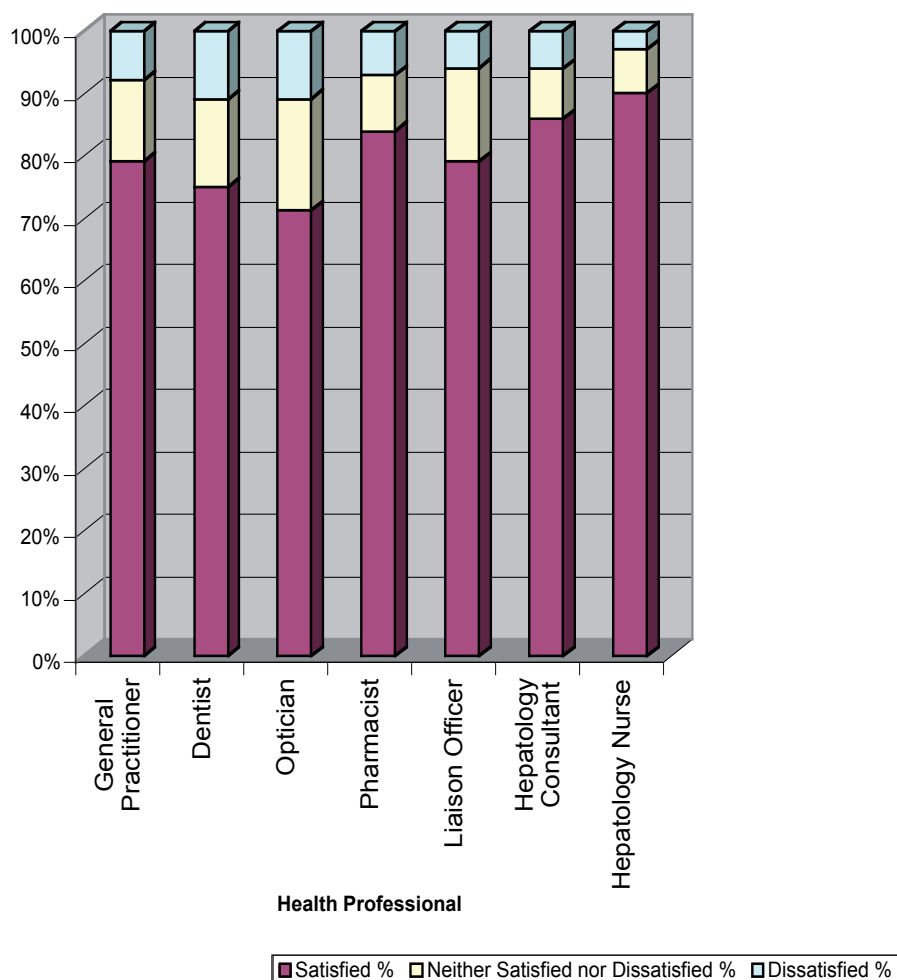
RECOMMENDATION 12

THAT PROGRESS ON THE RECOMMENDATIONS OF THIS REVIEW BE MONITORED ON AN ANNUAL BASIS FOR THREE YEARS WITH A REPORT SUMMARISING PROGRESS TO BE COMPLETED AT THE END OF THIS PERIOD. PROGRESS TO BE MONITORED BY A SUB-COMMITTEE OF THE CONSULTATIVE COUNCIL ON HEPATITIS C.

The Consultative Council on Hepatitis C of the Department of Health and Children led the initiative to implement the recommendations of the First Review by liaising with the various constituencies. These constituencies, in turn, have also monitored and worked on implementation of the 12 recommendations. This Second Review meets the requirement to overview progress after three years. A number of sources of information are readily available and this will increase in the coming years with initiatives such as the HPSC database. Some hepatology units identified the usefulness of performance indicators to track progress with the recommendations and recognised the need to set up additional systems to track and monitor targets. Liaison officers already collect data and disseminate it to hospital managers and front-line staff. The key role of the unit nurse in discharge planning, acting as the link between primary and secondary care, was noted. The role of the HPSC and the research database in monitoring progress was noted. Ideally, it was suggested, annual computer generated progress reports would provide the relevant information to all stakeholders nationally.

In terms of service user perspectives on progress on the recommendations overall, the support organisation survey asked some global questions which are useful as summaries of views of service users. Questions asked concerned overall satisfaction with health professionals; adequacy of health professional knowledge about hepatitis C entitlements and perceived changes in services since the First Review. Survey participants were asked how they rated their satisfaction with different health professionals (Figure 4). Most (90%) were satisfied with the hepatology nurse, followed by the hepatology consultant (86%) and the pharmacist (84%). Similar figures were obtained in the First Review. Eighty per cent were satisfied with both the GP and the liaison officer (the corresponding figure for the GP in the First Review was 89%). Levels for the dentist were 75% and 72% for the optician. Levels of dissatisfaction were low: 3% were dissatisfied with the hepatology nurse, 6% with both the liaison officer and the hepatology consultant, 7% with the pharmacist, 8% with the GP and 11% with both the dentist and the optician.

Figure 3.3: Overall Satisfaction with Health Professionals

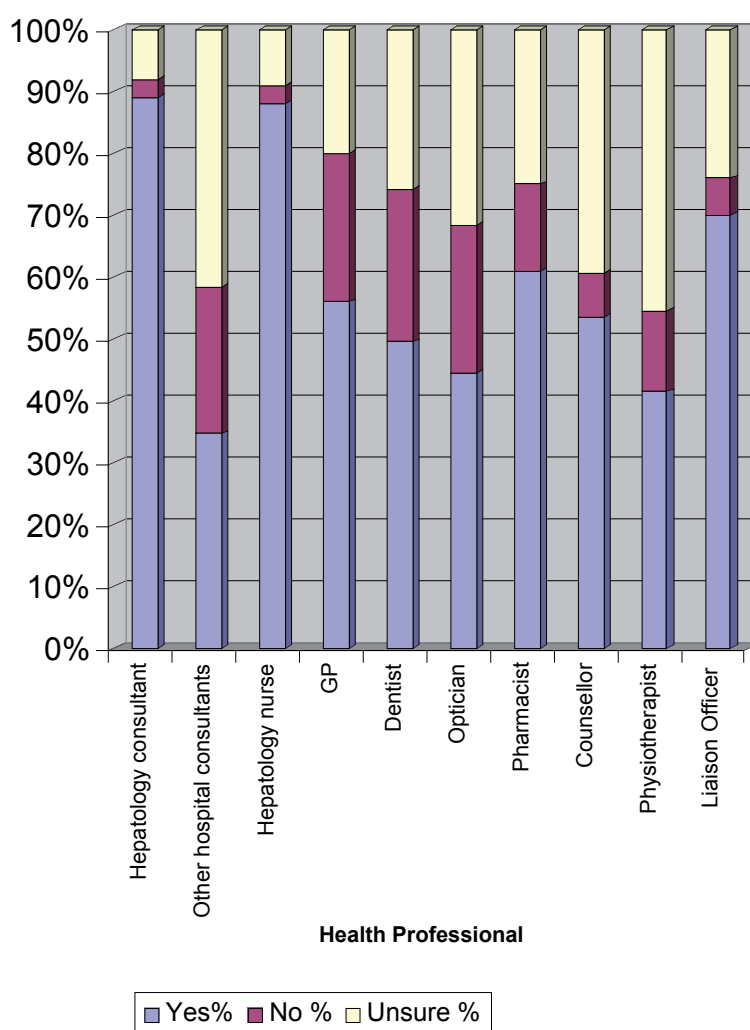


Regarding health professional knowledge on hepatitis C, the survey highlighted large differences in perceived adequacy. As Figure 3.4* shows, 89% considered the hepatology consultant adequately informed, followed closely by the hepatology nurse (88%). There was a large gap between these two and other health professionals. Seventy one per cent rated liaison officers as adequately informed, followed by pharmacists (61%) and GPs (56% - compared with 62% in the 1999 survey). Just over half of respondents (53%) rated counsellors as being adequately informed, with dentists at 50% (vs. 64% in the First Review), opticians at 45%, physiotherapists at 41% and other hospital consultants at 35%.

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* See also Table 1 in Appendix 3, page 70

Figure 3.4: Participant perceptions of adequacy of health professionals' knowledge about Hepatitis C

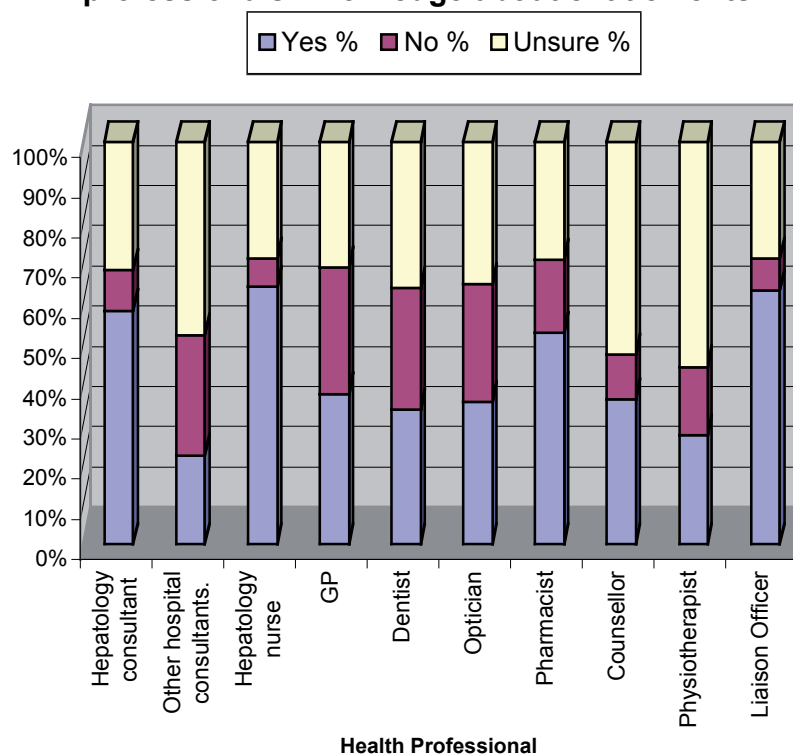


The survey highlighted significant differences in perception in relation to health professional knowledge about service user entitlements (Figure 3.5*). Almost two-thirds of respondents (64%) considered the liaison officer and the hepatology nurse were adequately informed about service entitlements. Next came the hepatology consultant (58%) and the pharmacist (53%). A wide gap exists between these and the other health professionals listed. Thirty seven per cent considered the GP adequately informed, 36% the optician, 35% the counsellor, 34% the dentist, with the physiotherapist and other hospital consultants at 27% and 22% respectively.

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* See also Table 2 in Appendix 3, Page 71

Figure 3.5: Participant perceptions of adequacy of health professionals' knowledge about entitlements

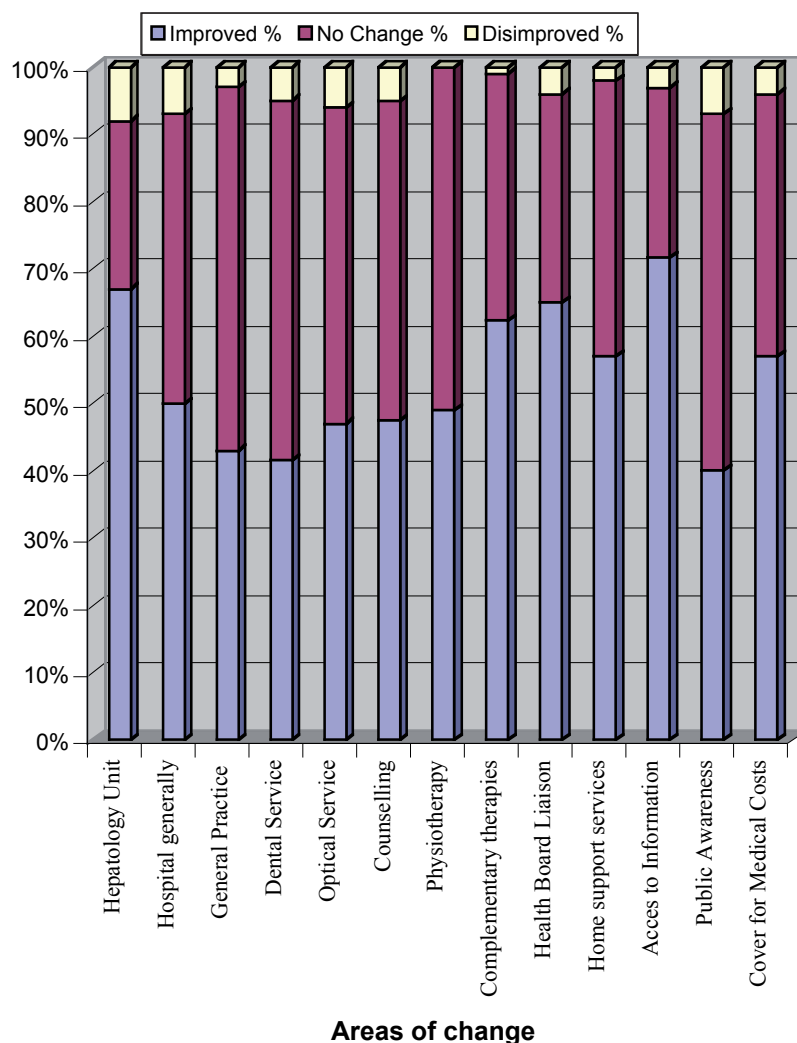


Finally, as a global indicator of progress between Reviews, participant views were sought as to what changes, if any, they had noticed in their health service since 1999 (i.e., over the past five years since the First Review) (Figure 3.6*). Many (71%) felt that access to information had improved. Two thirds (67%) felt the hepatology unit had improved, while almost as many (65%) felt the same in relation to health board liaison services. The figure for complementary therapy services was 63%, followed by home support services and financial coverage for medical costs (both at 57%). Next came general hospital services (50%) physiotherapy (49%), counselling and optical services (both at 47%), with general practice at 43% and dental services at 41%. Interestingly, 40% felt that public awareness of their condition had improved in the timeframe.

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* See also Table 3 in Appendix 3, page 72

Figure 3.6: Participant perceptions of changes in health and related services since the First Review



Conclusions: The recommendation to review progress on an ongoing basis has been taken up in a variety of ways in the past few years, e.g., regular meetings of the Department of Health and Children's Blood Policy Division, support organisation and liaison officer groups. This Second Review is the final aspect of this recommended monitoring of progress. For the future, the Health Protection Surveillance Centre organised Hepatitis C database will provide one additional form of regular and comprehensive review of progress. A further formal Review is advised in five years.

Recommendation K (Recommend maintenance – Second Review)

That progress on the recommendations of this Review be monitored on an ongoing basis for five years with a report summarising progress to be completed at the end of this period.

RESULTS II: New areas of concern

Introduction

This section addresses the second objective of the Review. Areas of most concern for the future and which have not been included in the Recommendations section (Results I) are outlined. These are - in no specific rank order as they all need consideration - home nursing needs and services, health promotion activities for those with hepatitis C, a mechanism for monitoring emerging developments into the future and the management of children and young people with iatrogenic hepatitis C. The latter is more correctly an ongoing issue but is new to consideration in this Review system as it was not part of the remit of the First Review.

Home Nursing Services

Home nursing can be considered in the context of serious, including terminal, illness. It facilitates the desire of the person concerned to remain at home for as long as possible when in ill-health or facing death. Home nursing has to date been developed mainly in cancer services. There are distinct challenges in nursing care and management in the context of home nursing for those with infectious diseases.

The demand for home nursing from the hepatitis C cohort to date has been small. However, the need for this service is likely to increase considerably in the medium to long term as the cohort becomes older and more unwell. In preparation for this anticipated need, a pilot scheme had commenced in the former Eastern Regional Health Authority. This involved the imminent recruitment of a Nurse Coordinator, whose brief includes employing a “bank” of nurses who will be trained and available in an “on call” system; providing education and training; and liaising with secondary care hepatology unit clinical nurse specialists. Some concern was expressed that the job description for this new role was very broad, to the extent that the person in this role would be ‘desk-bound’ and therefore akin to another liaison officer. Support organisations expressed a desire for the Nurse Coordinator to be able to attend meetings and be available to patients for support, possibly before the stage where home nursing is needed. A concern was expressed that if this coordinating role is for hepatitis C overall and not only for the State-infected cohort, that the person would become too busy with the general hepatitis C service, with services to persons with State-infected hepatitis C thus compromised.

A question was asked about use of, and need for, home nursing in the support organisation survey. It was clear from replies and written comments that many people were not familiar with the concept of home nursing and confused it with either extended home support services or public health nursing services. Future surveys will need to explain the concept when questioning about this service. An observation from support organisations was that home nursing is likely to be very popular choice in the future, in particular if there are concerns about the management of death in hospital or other ‘public’ settings. Specifically, if use of ‘body bags’ or other actions, which could compromise a person’s confidentiality or dignity, were anticipated, home nursing was seen as likely to be a preferred option.

Conclusion: Home nursing was identified by all constituents as an important emerging need. There has been little demand on this service to date, but it is anticipated that the need for this service will increase considerably in the medium to long term, as the patient cohort becomes older. The outcome of a pilot scheme currently underway in the former ERHA will be of considerable value to other regions in establishing a home nursing service. It is recommended that a home nursing service for hepatitis C be established nationally in the near future, prior to, and in anticipation of, increased demand for this service.

Recommendation L (New recommendation to prioritise – Second Review)

That a home nursing service for hepatitis C be established nationally in anticipation, and in advance of, increased demand.

Health Promotion

The issue of co-morbidity with other illnesses is an important one for persons with hepatitis C, as the combination of health conditions can significantly compromise overall well-being. Some of this co-morbidity can be avoided, or minimised, by appropriate and timely health promotion and lifestyle modification. There has been a notable increase in reported incidence of Type 2 diabetes in the cohort with State-infected hepatitis C. This is known to be a hepatitis C related condition, but is also a condition whose incidence increases with age and with weight gain. Appropriate health promotional interventions, therefore, may influence the incidence of diabetes and other conditions in this cohort, and will certainly influence management of the condition, once diagnosed.

Hepatology unit staff spoke of frequent requests from support organisations to make available a room in the unit for use to provide complementary therapies. However, unit staff suggested that the facilities and funding might be better used in providing specific, tailored health promotion in the context of preventing and/or managing co-morbidity. Specifically, units identified a need to have input from a dietitian. In some areas, the waiting list to see a dietitian was reported as being up to four months. This was seen to be unsatisfactory and potentially compromising of future well-being for persons with hepatitis C. Open-ended commentary from the survey also identified interest in availing of specialist dietetic and nutritional advice focusing on the hepatitis C condition. Such advice could be organised in large educational groups or paper version formats as well as in specific one-to-one consultations. Resources might be usefully spent in making some tailored advice available to all through paper, ‘classroom’ or electronic means, as well as ensuring access to appropriate health professionals (such as dietitians), as needed.

Conclusion: Lack of availability of health professionals to provide key health promotional intervention was identified by a number of constituents as an important current issue with emerging implications. In particular, issues of weight gain and increasing incidence of diabetes were identified. Difficulty in accessing dietitians was identified as a widespread problem. The importance of specific health promotional interventions was emphasised. It is recommended that access to necessary health care

professionals be organised so that appropriate, tailored health promotional interventions can be provided to promote health and well-being.

Recommendation M (New recommendation to address – Second Review)

That access to necessary health care professionals be organised so that appropriate, tailored health promotional interventions can be provided to promote health and well-being.

Monitoring Emerging Developments

Hepatitis C attracts significant research funding internationally, resulting in an evolving understanding of best practice in relation to care and management. Considerable changes have taken place since completion of the First Review in international recommendations, e.g., in the frequency of conducting liver biopsy (now decreased from on average two-yearly to every five years) and in the nature of drug therapy (from interferon alone to combination therapy). The rapid pace of change in scientific evidence provides ongoing challenges for evidence-based service delivery.

Conclusion: Given the evolving nature of hepatitis C treatment and management, there is a need to monitor national and international developments in the context of the Irish hepatitis C cohort. It is recommended that ongoing monitoring of emerging needs be conducted, alongside tracking of emerging therapies and changes in practice. This is likely to be the role of the Consultative Council with support from the relevant other constituencies, e.g., the Medical Consultant Sub-Committee, the Steering Committee of the national Hepatitis C Database, or support organisations.

Recommendation N (New recommendation to address – Second Review)

That ongoing monitoring of emerging needs be conducted, alongside tracking of emerging therapies and changes in practice in hepatitis C.

Children and young people with hepatitis C through State-provided blood products

The remit of the Second Review was extended to include Our Lady's Hospital for Sick Children (OLHSC) in Dublin. This is the designated national centre providing hepatology services to children and young people affected by iatrogenic hepatitis C. OLHSC provides services to c. 35-40 State-infected children (of a larger total of c. 200 children with hepatitis C). Most State-infected children have been infected through transfusion. Most are now in early adolescence. Although the word 'children' is used here, most of those described are now in adolescence.

Children typically have blood samples taken once yearly with consultant review. Families have direct access to the hospital service by telephone to the hepatology specialist nurse. Most notable about these children is that few have symptoms. Treatment is non-aggressive with combination therapy almost always reserved until

adulthood. Regarding research on hepatitis C in children, there is a European consortium on its management with multi-centre randomised trials underway in the US and the UK on aspects of hepatitis C management in children. The main psychosocial issue in this context concerns disclosure. Many parents have been reluctant to tell others about their child's hepatitis C diagnosis, including the child him/herself, other health professionals or others in the wider circle of the child's life. This choice by parents was felt to be challenging but manageable for hospital staff. For those who are aware of their diagnosis, many (adolescents) have concerns about relationships – implications of hepatitis C for intimate relationships with others and, in the future, marriage and children. These concerns are likely to continue and become more pertinent as these young people move into the young adult years. At approximately 18 years, but more specifically when children have completed Leaving Certificate examinations or an equivalent life milestone, they are referred to the adult hepatology centre of their choice. This transition is seen to work smoothly from the medical perspective although, as in other paediatric to adult clinical service transitions, some young people find the transition difficult in terms of adjusting to new staff, etc.

In terms of resources to the hospital, new offices and clinical facilities were completed on-site at OLHSC in December 2004. These facilities were funded in part from financial support for children with hepatitis C from State-infected blood. The specific role of Transfusion Positive in securing funding to enable the project to start was noted by hospital staff as being of particular importance in obtaining the new facilities. These new high quality facilities will enable a range of professional services needed for hepatitis C to be based in, and delivered from, one area in the hospital. This will facilitate more ongoing professional liaison among staff and will mean a one-stop centre for parents and children. The other useful resource of note by hospital staff was the booklet on Hepatitis C and Children, which was produced jointly by the Consultative Council on Hepatitis C and staff of the National Children's Liver Unit at Our Lady's Hospital for Sick Children in Crumlin, and supported by the Department of Health and Children.

Conclusion: Most of those currently attending OLHSC are now in their teenage years. Most are in good health. Emerging concerns relate to intimacy and relationship issues in the context of an infectious condition. Treatment decisions, such as whether to commence combination therapy, tend to be held over until adulthood. It is recommended that the challenges of young adulthood for this group be anticipated in order to assist professionals, young people themselves and their families in addressing their emerging concerns.

Recommendation O (New recommendation to address – Second Review)

That the challenges of young adulthood for this group be anticipated in order to assist professionals, young people themselves and their families in addressing their emerging concerns.

DISCUSSION AND CONCLUSION

This Second Review of services for those iatrogenically infected with hepatitis C in the Republic of Ireland summarises those recommendations from the First Review which are identified as current priorities to address and those which have become relatively routine and need maintenance rather than focussed attention at this time. Emerging issues of concern are also identified in this priority scheme. For conciseness, the recommendations are listed, with a brief explanation of each, in the Executive Summary at the front of the report.

In conclusion, there has been considerable progress in addressing the 12 recommendations of the First Review in the last five years. This reflects significant commitment, including financial investment and increasing cooperation across all sectors over time. It is acknowledged that expertise on hepatitis C has increased significantly in this country because of the iatrogenic infection of so many people; the difficult process of establishing accountability and services; and the subsequent investment in service delivery by all concerned. Many of the lessons learned here, in terms of coordinating services across the primary care sector for instance, can be usefully transferred to other aspects of the health system. Many of the issues which continue to be a challenge are those which cannot be solved for hepatitis C services in isolation. Complementary therapies and management of infection at the time of death are two such examples. Thus those committed to hepatitis C services specifically may need to work with, or be advocates for change in, other areas of service. Impending challenges for this hepatitis C group are also in part a result of, or are accentuated by, the challenges of ageing in this population. Thus this Second Review represents not an end but rather summarises what is a process that will continue over time with the evolving challenges of this hepatitis C population. The means to both influence and evaluate that process are inherent in the remit of the Consultative Council on Hepatitis C. Fundamentally, the Council has the remit to engage all of the relevant stakeholders in activities to ensure the planning and delivery of responsive and high quality services to this group for the foreseeable future.

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APPENDICES

APPENDIX 1.1

HEPATITIS C CONTRACTED THROUGH STATE INFECTED BLOOD AND BLOOD PRODUCTS – History and First Review

Hepatitis C is a relatively common blood-borne infectious disease. It has been estimated that 3% of the world's population is infected. Hepatitis C accounts for about 20% of cases of acute hepatitis and 70% of cases of chronic hepatitis. Its importance is that it is a major cause of cirrhosis and hepatocellular cancer⁴. End-stage liver disease secondary to hepatitis C virus infection is main reason for liver transplantation.

Following the discovery in February 1994 that anti-D immunoglobulin manufactured by the Irish Blood Transfusion Service Board was infected with hepatitis C, a number of screening programmes were put in place to identify those persons who had been infected, either directly or indirectly. It is estimated that about 1,600 persons were infected with hepatitis C through the administration of blood and blood products in the Republic of Ireland.

Acute hospital services for persons diagnosed positive for hepatitis C were put in place in 1994 in specialist hepatology (liver) units at six designated hospitals: Beaumont Hospital, the Mater Hospital, St Vincent's Hospital, Elm Park, and St James's Hospital in Dublin, Cork University Hospital, and University College Hospital in Galway. More recently, St Luke's Hospital in Kilkenny was included in the list of hospitals funded to provide specialist hepatology services. These services, provided under the Health Act (1970), are free of charge and include access to both in-patient and out-patient treatment as required.

On 23 September 1996, the Health (Amendment) Act (1996) came into effect. This legislation provided statutory entitlement to a range of primary health care services, free of charge, to persons who have contracted hepatitis C from the receipt of a blood product or blood transfusion. The services provided include general practitioner services, medicines, home nursing services, home support services, dental, ophthalmic, and aural services, as well as counselling services. At the request of the then Minister for Health, each health board appointed a liaison officer to ensure the efficient delivery of services under the Act, and to serve as a contact point for individuals and various interest groups whose members can avail of services under the Act. A Health Care Package for secondary services was also agreed between Positive Action and the Department of Health and Children in 1995. This covered entitlements to hospital treatments and sought to ensure sufficient funding, staffing, and facilities to provide high quality and appropriate secondary care services to those requiring them as a consequence of hepatitis C.

⁴ Marcellin P. The clinical spectrum of the disease. International consensus conference on hepatitis C (1) 1999; 1: 1-6.

CONSULTATIVE COUNCIL ON HEPATITIS C

The Consultative Council on Hepatitis C was established by the Minister for Health in November 1996 to advise and make recommendations to the Minister on all aspects of hepatitis C, including the organisation, delivery, and on-going review of services for persons with hepatitis C. The Council may advise and make recommendations on its own initiative, or at the request of the Minister.

REVIEW OF THE HEALTH SERVICES FOR PERSONS WITH HEPATITIS C

In 1998, the Council was requested by the Minister to oversee a major review of the health services - both secondary and primary - available to persons who contracted hepatitis C through the administration within the State of blood and blood products. The Health Services Research Centre, Department of Psychology, Royal College of Surgeons in Ireland was commissioned to conduct the review on the Council's behalf.

Review framework

The Council was concerned to ensure that the health services respond efficiently and effectively to the changing needs of persons with hepatitis C. In this regard, the current review involved:

- analysis of the services currently available, including their delivery;
- recommendations on how these services could be improved (with particular regard to the need for consistency of approach across the various hospitals and health boards); and
- recommendations on services, which should be provided to persons with hepatitis C.

The review involved consulting with a wide range of groups, including persons iatrogenically⁵ infected with hepatitis C, support groups, primary and secondary care providers, and State institutions. It assessed the structures, processes, and outcomes of current health services as perceived by these groups and developed recommendations, where appropriate, aimed at providing an effective and efficient service to meet evolving needs of persons with hepatitis C. Information was collected using a variety of methodologies in the following sequence: hospital chart review; focus groups of persons infected by different routes of infection; interviews with disease-specific support organisations; an interview-based survey of specialist unit registered patients⁶; interviews and postal surveys with health professionals; and interviews with national policy organisations.

The review aimed to provide a first national profile of:

- the population base and health service management of persons who contracted hepatitis C through State-provided blood products;
- the view of interested parties, as specified by the Consultative Council on Hepatitis C, on current service adequacy and future service needs.

From these consultations, twelve recommendations were developed to promote a coordinated, comprehensive, and accountable service ensuring the best achievable service for this unique group within the Irish health system in the coming years. These were included in a report of the Review (McGee et al, 2000). Recommendations were accepted by the Department of Health and Children and copies of the Review were widely distributed.

⁵ 'iatrogenic': where medical problems are induced by medical treatment of another condition. The term 'iatrogenic' here distinguishes those infected through State-provided blood products from persons infected through other means such as injecting illicit drugs.

⁶ the terms 'person with hepatitis C' and 'patient' are used interchangeably. As much of the discussion is about individuals' use of and views on services in the medical or health setting, the term 'patient' was considered appropriate.

APPENDIX 2.1

Consultation process for hepatitis C services review: those interviewed/consulted

Organisation	Personnel
Hospitals	
Beaumont Hospital, Dublin	<ul style="list-style-type: none"> • Dr Frank Murray, consultant gastroenterologist • Ms Eimear Bolger, clinical nurse specialist • Ms Marian Gilligan, unit secretary • Ms Lorraine Kernan, unit secretary
Cork University Hospital	<ul style="list-style-type: none"> • Dr Orla Crosbie, consultant hepatologist • Dr Elizabeth Kenny, locum consultant gastroenterologist • Ms Susan Corbett, clinical nurse specialist • Ms Natasha Clark, clerical officer • Ms Maria Scannell, clerical officer • Mr Neil Mackay, nurse services manager • Ms Maria J. McCarthy, patient services manager
Mater Hospital, Dublin	<ul style="list-style-type: none"> • Dr John Crowe, consultant gastroenterologist • Caroline Walsh, clinical nurse specialist • Ms Margaret McAndrews, unit secretary
St James's Hospital, Dublin	<ul style="list-style-type: none"> • Dr Suzanne Norris, consultant gastroenterologist • Helena Irish, clinic nurse specialist & clinic nurse manager & nurse counsellor • Ms Patricia Malone, business manager • Ms Carol-Ann Brogan, hepatology centre manager
St Luke's Hospital, Kilkenny	<ul style="list-style-type: none"> • Dr Gary Courtney, consultant physician and gastroenterologist • Ms Angela Buggy, clinical nurse specialist • Ms Pauline Carroll, clinical nurse specialist • Ms Anna Marie McDonald, unit secretary
St Vincent's Hospital, Dublin	<ul style="list-style-type: none"> • Ms Sheila O'Toole, clinical nurse specialist • Ms Carol Mc Nulty, clinical nurse specialist • Ms Georgina O'Reilly, unit secretary
University College Hospital, Galway	<ul style="list-style-type: none"> • Dr John Lee, consultant gastroenterologist • Ms Mary Bohan-Keane, clinical nurse specialist • Ms Margaret Seery, clinical nurse specialist • Ms Patricia Fitzpatrick, unit secretary
Our Lady's Hospital for Sick Children, Dublin	<ul style="list-style-type: none"> • Prof. Brendan Drumm, consultant gastroenterologist • Ms Fiona Wyley, clinical nurse specialist

Health boards*: Hepatitis C liaison officers (*now Health Service Executive regions)	
Eastern Regional Health Authority (Dublin)	<ul style="list-style-type: none"> ▪ Ms Anne Bartley, liaison officer, ▪ Mr Larry Bathe, liaison officer ▪ Ms Ann Tiernan, liaison officer ▪ Ms Valerie Whelan, primary care manager ▪ Mr John Fennell, primary care manager ▪ Ms Maria Fleming, regional liaison officer
Midland Health Board (Tullamore)	<ul style="list-style-type: none"> ▪ Mr P.J. Smyth, primary care unit manager & liaison officer
Mid-Western Health Board (Limerick)	<ul style="list-style-type: none"> ▪ Mr John Cullinane, primary care unit manager & liaison officer
North Eastern Health Board (Dundalk)	<ul style="list-style-type: none"> ▪ Ms Marie Mc Ginn, liaison officer
North Western Health Board (Manorhamilton)	<ul style="list-style-type: none"> ▪ Ms Helena Maguire, liaison officer ▪ Ms Sadie Flanagan, liaison officer
South-Eastern Health Board (Kilkenny)	<ul style="list-style-type: none"> ▪ Ms. Anne Marie Lanigan, GP unit manager & liaison officer ▪ Ms Breda Aylward, Liaison Officer
Southern Health Board (Cork)	<ul style="list-style-type: none"> ▪ Ms Ingrid Graef, liaison officer
Western Health Board	<ul style="list-style-type: none"> • Ms Catherine Cunningham, liaison officer

Organisation	Personnel
Support Groups	
Irish Haemophilia Society	<ul style="list-style-type: none"> ▪ Ms Margaret Dunne, administrator ▪ Ms Anne Duffy, counsellor
Irish Kidney Association	<ul style="list-style-type: none"> ▪ Ms Dorothy McCarthy, healthcare psychologist
Positive Action	<ul style="list-style-type: none"> ▪ Ms Josephine Mahoney, chairperson and committee members
Transfusion Positive	<ul style="list-style-type: none"> ▪ Ms Maura Long, chairperson & committee members

Relevant National Agencies	
Department of Health and Children: designated staff	<ul style="list-style-type: none"> Ms Ann McGrane, Ms Breda O'Connor, Mr Cormac Fitzgerald
Department of Health and Children: Consultative Council on Hepatitis C	<ul style="list-style-type: none"> Dr Elizabeth Kenny (Chair) Consultant in Gastroenterology and Hepatology, Cork University Hospital Ms Paula Kealy (Positive Action) Ms Siobhan O'Connor (Positive Action) Mr Michael Madigan (Transfusion Positive) Ms Mary Rowe (Transfusion Positive) Mr Mark Murphy Chief Executive (Irish Kidney Association) Ms Margaret Dunne (Irish Haemophilia Society) Ms Ann Broekhoven Director BUPA Mr John Murphy Laboratory Technician Cork Institute of Technology Prof Cliona O'Farrelly Director of the Education and Research Centre St. Vincent's University Hospital Mr John Cullinane Primary Care Unit Manager, Mid-Western Health Board Ms Ann McGrane Blood Policy Division Department of Health and Children Mr Ian Carter Deputy C.E.O. St James's Hospital Mr Paul O'Donoghue Psychologist, Central Remedial Clinic Dr Aiden McCormick Consultant Hepatologist, St. Vincent's University Hospital Ms Margaret Scarry Clinical Nurse Specialist University College Hospital Galway
Other Sources of Expertise	
National Disease Surveillance Centre (now the Health Protection Surveillance Centre of the Health Service Executive)	<ul style="list-style-type: none"> Dr Lelia Thornton Ms Aline Brennan

APPENDIX 2.2

Review: interview question guide on First Review Recommendations for professional and support organisation staff

[specific questions addressed to applicable groups and individuals]

Objectives of the Second Review

- 1) to examine the implementation of the specific recommendations made in the previous review;
- 2) to identify healthcare issues of concern which may have emerged since completion of this review.

Recommendation 1:

1. That a committee be established to agree treatment protocols (including liver biopsy procedures and scoring, and administration of anti-viral therapy) for this particular group. The committee should comprise the medical consultants with primary responsibility for this group of patients and be chaired on a rotating basis.

Questions:

- (i) *Since the last review, has this committee been established?*
- (ii) *Has the committee agreed protocols between the units?*
- (iii) *Has the committee chair rotated as suggested?*
- (iv) *Has progress been satisfactory, or are there areas of ongoing difficulty or concern?*
- (v) *Are there any further health care issues that have emerged which this committee could address?*
- (vi) *Is there anything else that you would like to document in relation to this recommendation?*

Recommendation 2:

2. That the system whereby patients are referred by their consultant hepatologist to another specialty be regularised to facilitate Hepatology Unit staff in making priority referrals in accordance with the 'two-week' rule. A comprehensive referral system for physiotherapy should be established to ensure that it is available to all who require it.

Questions:

- (i) *Since the last review, has the 'two-week' referral rule to specialties outside hepatology worked effectively?*
- (ii) *Are these priority referrals working similarly in each of the units nationally?*
- (iii) *Have the specific difficulties relating to physiotherapy referrals been addressed?*
- (iv) *Is there a comprehensive referral system to physiotherapy that works equally effectively throughout the country?*

- (v) *Is there anything else that you would like to document in relation to this recommendation?*

Recommendation 3:

3. That guidelines be developed for the management of death, including funeral arrangements, so that the necessary safe practices are understood and accepted by all concerned.

Questions:

- (i) *What are the current arrangements relating to management of death of a person with hepatitis C?*
- (ii) *Have guidelines been developed which inform relevant personnel about management of death, including funeral arrangements?*
- (iii) *If guidelines are not available, is satisfactory progress being made in relation to their development?*
- (iv) *Are there any ongoing difficulties or concerns about people's understanding of safe practice with regard to management of death?*
- (v) *Are there any new issues that have emerged in relation to this issue since completion of the last review?*
- (vi) *Is there anything else that you would like to document in relation to this recommendation?*

Recommendation 4:

4. That health board liaison officers meet on a regular basis to ensure uniformity and continuity in the provision of primary health care services.

Questions:

- (i) *Are health board liaison officers meeting on a regular basis?*
- (ii) *Is there uniformity and continuity nationally in the provision of primary health care services, e.g., general practice, dentist, pharmacy?*
- (iii) *Has progress been satisfactory in relation to implementing this recommendation, or are there areas of ongoing difficulty or concern?*
- (iv) *Are there any further health care issues that have emerged which your group could address?*
- (v) *Is there anything else that you would like to document in relation to this recommendation?*

Recommendation 5:

5. That health board liaison officers ensure choice of counsellors and counselling locations in all health board areas.

Questions:

- (i) *Is there now a choice of counsellors in all health board areas?*
- (ii) *Do clients have a choice in relation to where they see the counsellor, or are they limited to a single location in that health board area?*
- (iii) *Has progress been satisfactory in relation to implementing this recommendation, or are there areas of ongoing difficulty or concern?*
- (iv) *Are there any new issues that have emerged in relation to counselling since completion of the last review?*
- (v) *Is there anything else that you would like to document in relation to this recommendation?*

Recommendation 6:

6. That a general training programme for all home support providers be available. This programme must have as a basis an agreed strategy regarding the balance to be achieved between duty of care to the provider and the right to confidentiality of health information of the recipient.

Questions:

- (i) *What is the current situation in relation to accessing home support?*
- (ii) *Is there a general training programme made available for all home support providers?*
- (iii) *Is attendance at this training programme mandatory?*
- (iv) *Does this training programme affect the right to confidentiality of health information of the person receiving the service?*
- (v) *Has progress in relation to implementing this recommendation been satisfactory, or are there areas of ongoing difficulty or concern?*
- (vi) *Have any new issues emerged in relation to this recommendation since completion of the last review?*
- (vii) *Is there anything else that you would like to document in relation to this recommendation?*

Recommendation 7:

7. That the issues surrounding the difficulty in recruitment of home support providers, including remuneration issues, be reviewed to ensure availability of the service to all who require it.

Questions:

- (i) *Has progress been satisfactory in relation to implementing this recommendation or are there ongoing difficulties or concerns in relation to provision of home support?*
- (ii) *How are these difficulties being managed?*
- (iii) *Are there difficulties relating to remuneration of home support providers?*
- (iv) *Are home support providers remunerated similarly across all health board areas?*

- (v) *Have any new health care issues emerged in relation to this recommendation since completion of the last review?*
- (vi) *Is there anything else that you would like to document in relation to this recommendation?*

Recommendation 8:

8. That staff in all primary care disciplines dealing with this patient group (including general practitioners, dentists and pharmacists) be adequately informed about the actual risk of transmission of hepatitis C and the guidelines on universal precautions against transmission of infection; this is to ensure that such patients are treated in a sensitive manner.

Questions:

- (i) *Are you aware of the distribution of guidelines on universal precautions against transmission of infection to all primary health care disciplines?*
- (ii) *Have efforts been made to adequately inform primary care disciplines about the actual risk of transmission of hepatitis C?*
- (iii) *Are people with hepatitis C treated sensitively when interacting with primary care disciplines?*
- (iv) *Are there areas of ongoing difficulty or concern?*
- (v) *Have any new issues emerged in relation to primary health care service provision since completion of the last review?*
- (vi) *Is there anything else that you would like to document in relation to this recommendation?*

Recommendation 9:

9. That the role of complementary or alternative therapies in the management of hepatitis C be reviewed as part of a wider framework of evaluation of the use of such therapies in the Irish health system.

Questions:

- (i) *Has there been a review of the role of complementary or alternative therapies in hepatitis C management?*
- (ii) *Has progress been satisfactory in relation to this review or are there areas of ongoing difficulty or concern?*
- (iii) *Have new issues emerged in relation to complementary or alternative therapies since completion of the last review?*
- (iv) *Is there anything else that you would like to document in relation to this recommendation?*

Recommendation 10:

10. That a national database be established for research purposes; this to be located at an independent coordinating agency and run in association with relevant groupings.

Questions:

- (i) *Is there in existence a national database established for research purposes?*
- (ii) *Has progress been satisfactory in relation to implementation of this recommendation, or are there areas of ongoing difficulty or concern?*
- (iii) *Have any new issues emerged in relation to implementing this recommendation since completion of the last review?*
- (iv) *Is there anything else that you would like to document in relation to this recommendation?*

Recommendation 11:

11. That assurances be given that adequate funding and resources will continue to be provided to ensure a quality health care service for this patient group.

Questions:

- (i) *Have assurances been given that ongoing adequate funding and resources will be provided to ensure quality health care provision for people with hepatitis C?*
- (ii) *In what form have these assurances come?*
- (iii) *Is progress in this area satisfactory or are there ongoing difficulties or concerns?*
- (iv) *Is there anything else that you would like to document in relation to this recommendation?*

Recommendation 12:

12. That progress on the recommendations of this Review be monitored on an annual basis for three years with a report summarising progress to be completed at the end of this period. Progress to be monitored by a sub-committee of the Consultative Council on Hepatitis C.

Questions:

- (i) *Have there been efforts to monitor annually the implementation of the recommendations of the 2000 review?*
- (ii) *Is there anything else that you would like to document in relation to this recommendation?*

Appendix 2.3

Survey Questionnaire for Persons with Hepatitis C from State-infected blood or blood products

Health Amendment Act Health Services Review 2004

Section A: Demographic Details

- A.1) Sex ☐ Male ☐ Female
- A.2) Age _____ years
- A.3) Where do you live ☐ City/Large Town ☐ Small Town/Village ☐ Rural
- A.4) Marital Status
 ☐ Married ☐ Separated/Divorced ☐ Widowed ☐ Single
- A.5) Number of Children _____
- A.6) Current Status
 ☐ Employed ☐ Housewife ☐ On disability benefit (non Hepatitis C)
 ☐ Unemployed ☐ Retired ☐ On Hepatitis C related benefit

Section B: Clinical Details

- B.1) Year of Infection _____
- B.2) Year of diagnosis _____
- B.3) PCR Status
 ☐ Positive ☐ Negative ☐ Negative after Treatment
- B.4) Do you have a Health Amendment Act card?
 ☐ Yes ☐ No
- B.5) Chronic Illness: do you currently have any other serious chronic illness?
 ☐ Yes ☐ No
- B.6) How would you describe your overall health at the moment?
 ☐ Very Good ☐ Good ☐ Fair ☐ Poor
- B.7) How, in general would you rate your satisfaction with specialist Hepatitis C outpatient services (i.e. the Liver Unit, or Hepatology Clinic)?
 ☐ Extremely Satisfied ☐ Quite Satisfied ☐ Neither Satisfied nor Dissatisfied
 ☐ Quite Dissatisfied ☐ Extremely Dissatisfied

B.8) How many times have you attended hospital Hepatitis C outpatient services visits in the last year (from September 2003 to August 2004)?
_____ Number of Outpatient Visits

B.9) Have the number of outpatient Hepatitis C visits per year changed in the last 5 years?

- ☐ No – about the same number of visits now
☐ Yes – more visits now
☐ Yes – less visits now

B.10) Are you satisfied with the frequency of your visits?

- ☐ Yes, I am satisfied
☐ No, I would like to visit less frequently
☐ No, I would like to visit more frequently

B.11) What distance (in miles) do you travel to and from the Hepatitis C clinic (round trip)?
_____ miles

B.12) Do you have any difficulties with travel to use the following services at the moment?

Hospital Clinics	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Have not used this service in the last year
Physiotherapy	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Have not used this service in the last year
Counselling	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Have not used this service in the last year
Alternative Therapies	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Have not used this service in the last year
Any Other Service	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Have not used this service in the last year

Please name Service:

B.13) Do you feel you have received the best quality of care available in the last year? (September 2003-August 2004)

- ☐ Yes ☐ No ☐ Don't know

Explain if necessary:

B.14a) Have you changed hepatology units in the last year?

- ☐ Yes ☐ No

B.14b) How do you feel the quality of care you receive in the unit you currently attend compares with that in other hospital hepatology units?

- ☐ Better than others ☐ Same ☐ Worse than other units

What are your views of the following aspects of your experiences at the Hepatitis C clinic?

B.15) The amount of time you spend with the doctor
☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor ☐ Does not apply

B.16) The thoroughness of care you receive from staff
☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor ☐ Does not apply

B.17) The respect shown for your privacy
☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor ☐ Does not apply

B.18) The physical surroundings of the clinic
☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor ☐ Does not apply

The following questions relate to your satisfaction with your communication with Hepatitis C staff at the clinic. Please rate your satisfaction with the following aspects of this communication:

B.19) Your overall satisfaction with the information given to you in the clinic
☐ Extremely Satisfied ☐ Quite Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Quite Dissatisfied ☐ Extremely Dissatisfied

B.20) Your opportunity to ask questions at the clinic
☐ Extremely Satisfied ☐ Quite Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Quite Dissatisfied ☐ Extremely Dissatisfied

B.21) The explanations given to you about the tests and procedures that you undergo
☐ Extremely Satisfied ☐ Quite Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Quite Dissatisfied ☐ Extremely Dissatisfied

B.22) The explanations given about your test results and progress
☐ Extremely Satisfied ☐ Quite Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Quite Dissatisfied ☐ Extremely Dissatisfied

B.23) The opportunity to contact the clinic in between appointments
☐ Extremely Satisfied ☐ Quite Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Quite Dissatisfied ☐ Extremely Dissatisfied

B.24) Have you experienced any problem or concerns using the Health Amendment Act card in relation to any service in the last year (from September 2003-August 2004)?

☐ Yes ☐ No

If yes, please explain:

Section C: Procedures and Treatment

C.1) Biopsy

C.1)(a) Have you attended hospital for liver biopsy in the last year (September 2003-August 2004)?

☐ Yes ☐ No (If No, skip to Question C.2)

C.1)(b) If yes, how long did you spend in hospital when having the liver biopsy?

- a) Day case ☐
- b) Overnight, the night before ☐
- c) Overnight, the night after ☐
- d) Overnight, both the night before and after ☐

C.1)(c) Were you given a choice about having a biopsy as a day case or as an inpatient?

☐ Yes ☐ No

C.1)(d) What was your overall satisfaction with length of stay when having a liver biopsy?

☐ Extremely Satisfied ☐ Quite Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Quite Dissatisfied ☐ Extremely Dissatisfied

C.2) Combination Therapy

C.2)(a) Have you undergone combination therapy for Hepatitis C in the last year? (September 2003-August 2004)

☐ No (Skip to question C.3)
☐ No – but planning to (skip to question C.3)
☐ Yes

C.2)(b) Were you given the opportunity to stay in hospital when combination therapy was initiated?

☐ Yes ☐ No

If yes – how many days did you stay? _____ Days

C.2)(c) Was your stay:

☐ Adequate ☐ Too long ☐ Too short

C.2)(d) What was your general mood while on combination therapy?

☐ Good ☐ Fair (occasionally depressed) ☐ Poor (often depressed)
☐ Very Poor (depressed all of the time) ☐ Extremely Poor (considered suicide)

C.2)(e) I was satisfied with the level of medical support available to me while on combination therapy

☐ Strongly Agree ☐ Agree ☐ Neither Agree or Disagree
☐ Disagree ☐ Strongly Disagree

C.2)(f) I was satisfied with the monitoring of side effects of combination

☐ Strongly Agree ☐ Agree ☐ Neither Agree or Disagree
☐ Disagree ☐ Strongly Disagree

C.2)(g) I was satisfied with the level of counselling support available to me while on combination therapy

- ☐ Strongly Agree ☐ Agree ☐ Neither Agree or Disagree
☐ Disagree ☐ Strongly Disagree

C.2)(h) Your overall satisfaction with receiving combination therapy

- ☐ Extremely Satisfied ☐ Quite Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Quite Dissatisfied ☐ Extremely Dissatisfied

C.3) Other Hospital Visits

C.3)(a) Have you been admitted to hospital in the last year (September 2003-August 2004) for treatment other than biopsy or combination therapy?

- ☐ Yes ☐ No (If No, skip to question C.3(c))

C.3)(b) If yes, overall how satisfied were you with your hospital stay?

- ☐ Extremely Satisfied ☐ Quite Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Quite Dissatisfied ☐ Extremely Dissatisfied

C.3)(c) If you were referred to other specialists or services in the last year (September 2003-August 2004), were you seen within 2 weeks of referral?

- ☐ Yes ☐ For some but not all first appointments
☐ No ☐ No referrals needed (Skip to Section D)

C.3)(d) Satisfaction with time waiting for referral

- ☐ Extremely Satisfied ☐ Quite Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Quite Dissatisfied ☐ Extremely Dissatisfied

Section D: Primary Care Services

D1) Counselling Services

D.1)(a) Have you availed of counselling services in the last year (September 2003-August 2004)?

- ☐ Yes ☐ No (If No, skip to question D.1(c))

D.1)(b) Your overall satisfaction with counselling

- ☐ Extremely Satisfied ☐ Quite Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Quite Dissatisfied ☐ Extremely Dissatisfied

D.1)(c) Have any other members of your family attended counselling for Hepatitis C in the last year (September 2003-August 2004)?

- ☐ Yes ☐ No (If No, skip to section D.2)

D.1)(d) Were they satisfied with having counselling?

- ☐ Extremely Satisfied ☐ Quite Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Quite Dissatisfied ☐ Extremely Dissatisfied

D.2) Physiotherapy Services

D.2)(a) Have you availed of physiotherapy services in the last year (September 2003-August 2004)?

- ☐ No (If No, skip to section D.3)
☐ Yes – public stream
☐ Yes – privately

D.2)(b) Your overall satisfaction with physiotherapy?

- ☐ Extremely Satisfied ☐ Quite Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Quite Dissatisfied ☐ Extremely Dissatisfied

D.3) Alternative or Complementary Therapies for Hepatitis C

D.3)(a) Did you find it easy to access complementary therapies?

- ☐ Yes ☐ No

D.3)(b) Have you used complementary therapies for Hepatitis C in the last year (September 2003-August 2004)?

- ☐ Yes ☐ No (If No, skip to question D.4)

D.3)(c) If yes, what therapies have you tried?

- ☐ Reflexology ☐ Massage ☐ Aromatherapy ☐ Special Diets ☐ Chiroprody
☐ Homeopathy ☐ Other (please specify):

D.3)(d) Have you been reimbursed for these services?

- ☐ Yes – I paid and was reimbursed promptly
☐ Yes – I paid and was reimbursed but had to wait more than a month
☐ No – I paid but was not able to get reimbursement
☐ No – I did not have to pay for the service

D.3)(e) Your overall satisfaction with having complementary therapies

- ☐ Extremely Satisfied ☐ Quite Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Quite Dissatisfied ☐ Extremely Dissatisfied

D.4 Information

D.4)(a) Do you find that health professionals are adequately informed about Hepatitis C and about service entitlements?

	Adequately informed about condition			Adequately informed about service entitlements		
Hepatology Consultant	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure	<input type="checkbox"/> Yes	No	<input type="checkbox"/> Unsure
Other Hospital Consultants	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure	<input type="checkbox"/> Yes	No	<input type="checkbox"/> Unsure
Hepatology Nurse	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure	<input type="checkbox"/> Yes	No	<input type="checkbox"/> Unsure

General Practitioner	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
Dentist	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
Optician	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
Pharmacist	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
Counsellor	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
Physiotherapist	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
Liaison Officer	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure

Please indicate your views on the following statements:

D.4)(b) The staff in the pharmacy is informed about the Health Amendment Act Card

- ☐ Strongly Agree ☐ Agree ☐ Neither Agree or Disagree
☐ Disagree ☐ Strongly Disagree

D.4)(c) The staff in the pharmacy is discreet when I use the Health Amendment Act Card

- ☐ Strongly Agree ☐ Agree ☐ Neither Agree or Disagree
☐ Disagree ☐ Strongly Disagree

D.4)(d) How would you rate your overall satisfaction with these services?

General Practitioner

- ☐ Very Satisfied ☐ Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Dissatisfied ☐ Very Dissatisfied

Dentist

- ☐ Very Satisfied ☐ Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Dissatisfied ☐ Very Dissatisfied

Optician

- ☐ Very Satisfied ☐ Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Dissatisfied ☐ Very Dissatisfied

Pharmacist

- ☐ Very Satisfied ☐ Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Dissatisfied ☐ Very Dissatisfied

Liaison Officer

- ☐ Very Satisfied ☐ Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Dissatisfied ☐ Very Dissatisfied

Hepatology Consultant

- ☐ Very Satisfied ☐ Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Dissatisfied ☐ Very Dissatisfied

Hepatology Nurse

- ☐ Very Satisfied ☐ Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Dissatisfied ☐ Very Dissatisfied

Section E: Entitlements

Home Support/Home Help

E.1) Have you used health board or other paid home support/home help in the last year?
(From September 2003 to August 2004)

- ☐ No (If No, skip to question E.4(a))
☐ Yes – Health Board provided and paid
☐ Yes – paid by me (reimbursed by Health Board)

E.2) If yes, how many hours of home support/home help per week do you have?
_____ hours

E.3) How satisfied are you with the service?

- ☐ Very Satisfied ☐ Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Dissatisfied ☐ Very Dissatisfied

E.4)(a) Have you needed and/or used home nursing services in the past year?

- ☐ Not needed (If not needed, skip to question E.5)
☐ Needed, but not used, why not?

- ☐ Needed and used

E.4)(b) If used, how satisfied were you with the service?

- ☐ Very Satisfied ☐ Satisfied ☐ Neither Satisfied nor Dissatisfied
☐ Dissatisfied ☐ Very Dissatisfied

E.5) In the last year, have you ever not used the services because of having to pay first and wait for reimbursement?

- ☐ No ☐ Yes (which services)?

Section F: Summary

F.1) Stigma

Some people feel stigmatized when they have an ongoing medical condition. Would you say at the moment you feel stigmatized?

- ☐ Very much indeed ☐ Quite a lot ☐ Not very much ☐ Not at all

F.2) Services for Hepatitis C have been developing since 1994. These services were reviewed in a previous Consultative Council review in 1999. What is your view of changes, if any, in the last 5 years (since 1999) in the following services?

F.2)(a) Hepatology Unit (Hepatitis C clinic)

- ☐ Improved significantly ☐ Improved ☐ No change
☐ Disimproved ☐ Disimproved significantly

F.2)(b) Hospital Generally

- ☐ Improved significantly ☐ Improved ☐ No change
☐ Disimproved ☐ Disimproved significantly

F.2)(c) General Practice

- ☐ Improved significantly ☐ Improved ☐ No change
☐ Disimproved ☐ Disimproved significantly

F.2)(d) Dental Services

- ☐ Improved significantly ☐ Improved ☐ No change
☐ Disimproved ☐ Disimproved significantly

F.2)(e) Optical Services

- ☐ Improved significantly ☐ Improved ☐ No change
☐ Disimproved ☐ Disimproved significantly

F.2)(f) Counselling

- ☐ Improved significantly ☐ Improved ☐ No change
☐ Disimproved ☐ Disimproved significantly

F.2)(g) Physiotherapy

- ☐ Improved significantly ☐ Improved ☐ No change
☐ Disimproved ☐ Disimproved significantly

F.2)(h) Complementary Therapies

- ☐ Improved significantly ☐ Improved ☐ No change
☐ Disimproved ☐ Disimproved significantly

F.2)(i) Health board Liaison

- ☐ Improved significantly ☐ Improved ☐ No change
☐ Disimproved ☐ Disimproved significantly

F.2)(j) Home Support/Home Help Services

- ☐ Improved significantly ☐ Improved ☐ No change
☐ Disimproved ☐ Disimproved significantly

F.2)(k) Access to Information

- ☐ Improved significantly ☐ Improved ☐ No change
☐ Disimproved ☐ Disimproved significantly

F.2)(l) Public Awareness

- ☐ Improved significantly ☐ Improved ☐ No change
☐ Disimproved ☐ Disimproved significantly

F.2)(m) Financial Coverage for Medical Costs

- ☐ Improved significantly ☐ Improved ☐ No change
☐ Disimproved ☐ Disimproved significantly

F.3) Are there any services you would like to have used in the past year but did not do so?

Type of Service	Reason why this was not used

Thank you very much for your help.

Appendix 3.1:
Table 1: Participant perceptions of adequacy of health professionals' knowledge about hepatitis C

	Hepatology consultant	Other hospital consultants	Hepatology nurse	GP	Dentist	Optician
TOTAL (N)	402	350	380	411	389	385
Yes (%) (N)	89 (360)	35 (121)	88 (336)	56 (227)	50 (195)	45 (170)
No (%) (N)	3 (12)	24 (82)	3 (11)	24 (101)	25 (94)	24 (92)
Unsure (%) (N)	8 (30)	42 (147)	9 (33)	20 (83)	26 (100)	32 (123)

Table 1 (contd.): Participant perceptions of adequacy of health professionals' knowledge about hepatitis C

	Pharmacist	Counsellor	Physio-therapist	Liaison officer
TOTAL (N)	390	254	267	365
Yes (%) (N)	61 (236)	53 (137)	41 (111)	70 (255)
No (%) (N)	14 (57)	7 (19)	13 (36)	6 (22)
Unsure (%) (N)	25 (97)	39 (99)	45 (120)	24 (88)

Table2: Participant perceptions of adequacy of health professionals' knowledge about entitlements

	Hepatology consultant	Other hospital consultants	Hepatology nurse	GP	Dentist	Optician
TOTAL (N)	312	291	296	314	301	299
Yes (%) (N)	58 (180)	22 (63)	64 (190)	37 (115)	33 (101)	35 (105)
No (%) (N)	10 (32)	30 (87)	7 (20)	31 (98)	30 (89)	29 (86)
Unsure (%) (N)	32 (100)	48 (141)	29 (86)	31 (101)	36 (111)	35 (108)

Table 2 (contd.): Participant perceptions of adequacy of health professionals' knowledge about entitlements

	Pharmacist	Counsellor	Physio-therapist	Liaison officer
TOTAL (N)	294	222	233	282
Yes (%) (N)	52 (154)	36 (80)	27 (63)	63 (176)
No (%) (N)	18 (54)	11 (24)	17 (40)	8 (23)
Unsure (%) (N)	29 (86)	53 (118)	56 (130)	29 (83)

Table 3: Participant perceptions of changes in health and related services since the First Review

	Hepatology Unit	Hospital generally	General Practice	Dental service	Optical service	Counselling	Physiotherapy	Complementary therapies
TOTAL (N)	424	387	421	384	379	211	207	217
Improved (%) (N)	67 (285)	50 (196)	43 (179)	42 (158)	47 (176)	47 (100)	49 (103)	63 (135)
No Change (%) (N)	25 (106)	43 (164)	54 (228)	54 (207)	47 (181)	47 (99)	51 (104)	37 (80)
Disimproved (%) (N)	8 (33)	7 (27)	3 (14)	5 (19)	6 (22)	5 (12)	0 (0)	1 (2)

Table 3: (contd.): Participant perceptions of changes in health and related services since the First review

	Health Board Liaison	Home support services	Access to information	Public awareness	Financial cover for medical costs
TOTAL (N)	362	303	421	415	389
Improved (%) (N)	65 (233)	57 (172)	71 (302)	40 (164)	57 (225)
No Change (%) (N)	31 (114)	41 (146)	25 (106)	53 (221)	39 (150)
Disimproved (%) (N)	4 (15)	2 (5)	3 (13)	7 (30)	4 (14)