# Hepatitis C Action Plan for Scotland
# Phase II: May 2008 – March 2011

The Scottish Government, Edinburgh 2008

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The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

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# Contents

## Foreword

We are both delighted to present the Phase II Hepatitis C Action Plan. When the first Hepatitis C Action Plan was published in September 2006, the intention at that time was to raise awareness of Hepatitis C as a significant public health issue, and to increase the evidence base around the disease and the services available in Scotland. After two years of hard work all but one of the 41 actions in the first Action Plan have been, or will shortly be, completed. A lot has been learned and, over the past six months, colleagues in NHS Health Protection Scotland and elsewhere have been working hard to develop that learning into a series of actions for the next three years. The Action Plan presented here is the product of that work.

In the foreword to the first Action Plan we acknowledged that Hepatitis C is a complex problem, that existing services would likely need to change if we wanted to tackle the disease successfully, and that investment was key. With Phase II comes major Government investment - £43 million over three years. This underpins the proposed actions which set out the ways in which the NHS and others need to change and evolve to better tackle Hepatitis C.

A significant strand of the plan is about improving testing, treatment, care and support services for those infected, with a major emphasis being placed on increasing the number of people receiving treatment. The plan also recognises and addresses the social care needs and drug addiction problems of infected persons through actions aimed at improving links between clinical, addiction and mental health services.

The importance of prevention is acknowledged through several actions, particularly those designed to reduce the sharing of needles/syringes and other injecting equipment by injecting drug users.

Our investment will also provide a step change in the monitoring and surveillance activities currently undertaken, ensuring that we can actively monitor and assess progress and success over the coming three years.

In all, the Hepatitis C Phase II Action Plan amounts to intervention on an industrial scale; an investment in the public health of Scotland that should, over the longer term, significantly reduce the problem of Hepatitis C in Scotland.

None of this would have been possible without the excellent work carried out by Professor David Goldberg and his colleagues at NHS Health Protection Scotland. Our thanks also go to the four chairs of the Working Groups established to support Phase I of the Hepatitis C Action Plan, whose hard work has contributed significantly to the development: Dr Syed Ahmed; Dr John Dillon; Mr George Howie; and Professor Avril Taylor.

With this Phase II Action Plan, Scotland is leading the way in the UK and is at the forefront of action in Europe in tackling Hepatitis C. Moreover, in this 60th Anniversary Year of the National Health Service, this Action Plan is an example of the NHS at its best: working with its key partners to significantly improve the health of the people of Scotland.

**Minister for Public Health** **Chief Medical Officer**

## Abbreviations

| | |
|---|---|
| APCG | Action Plan Co-ordinating Group |
| BBVs | Blood Borne Viruses |
| CHP | Community Health Partnership |
| GP | General Practitioner |
| HIV | Human Immunodeficiency Virus |
| HPA | Health Protection Agency |
| HPS | Health Protection Scotland |
| IDUs | Injecting Drug Users |
| IGI | Information Generating Initiatives |
| MCN | Managed Care Network |
| NGO | Non Governmental Organisation |
| NHS | National Health Service |
| NICE | National Institute for Health and Clinical Excellence |
| QIS | Quality Improvement Scotland |
| SIGN | Scottish Intercollegiate Guidelines Network |
| SPS | Scottish Prison Service |
| UK | United Kingdom |
| WTE | Whole Time Equivalent |

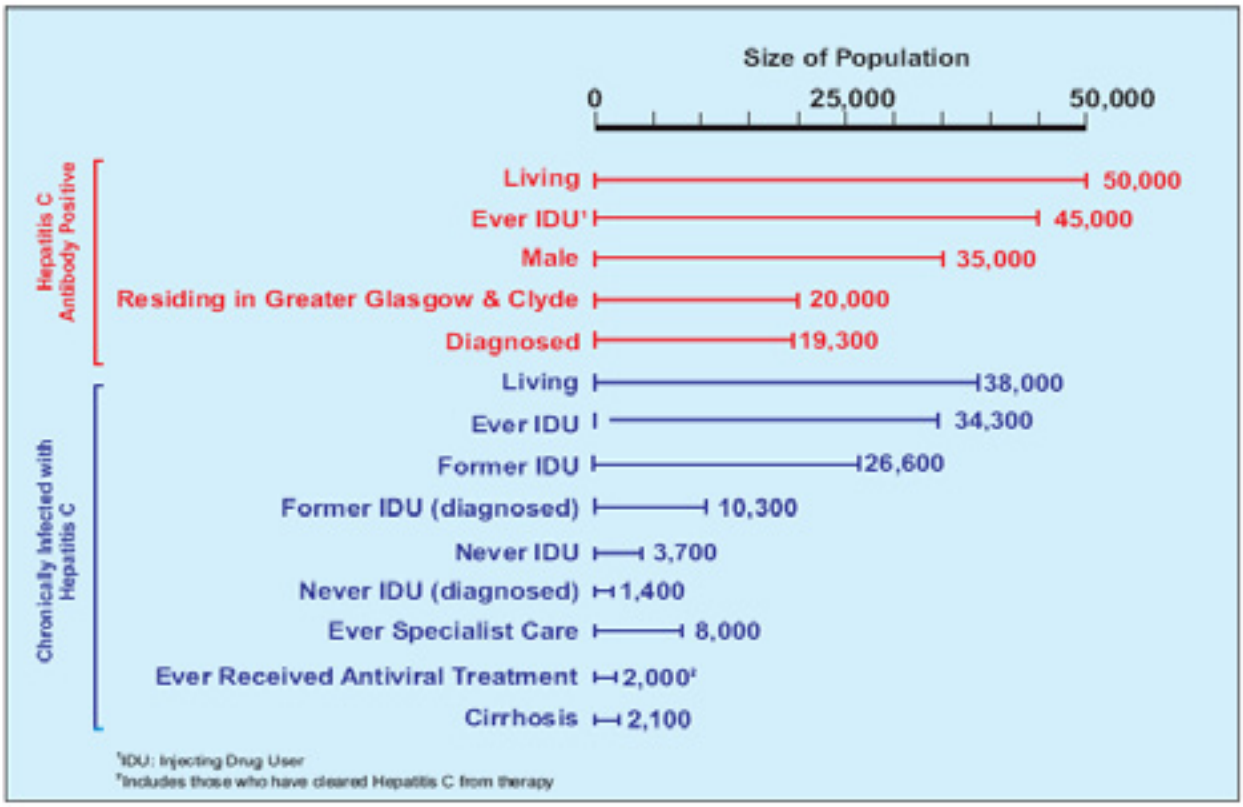
## Acknowledgements

It is impossible to thank, individually, the hundreds of people who have made contributions to Scotland's Hepatitis C Action Plan. Special thanks, however, should be conveyed to members of the Action Plan Co-ordinating Group, it's three Working Groups, the Implementation Group and the Hepatitis C Executive Leads Group (see Appendices), all of whom have been responsible for implementing Phase I actions and developing the Action Plan for Phase II. Thanks also to Kerry Chalmers and John Froggatt who facilitated much of the Phase I process at a Government level and to Dawn Griesbach who also laid many of the foundations for Phase II through her contribution in developing the Phase I Plan.

# Introduction

In 2004, the Scottish Government recognised that "Hepatitis C is one of the most serious and significant public health risks of our generation". [1] By December 2006, Health Protection Scotland (HPS) estimated that 50,000 persons in Scotland had been infected with the Hepatitis C virus and that 38,000 were chronic carriers (Figure 1). [2,3]

**Figure 1: Hepatitis C epidemiological landscape (estimates): Scotland, 2006.**




Around 90% of those infected acquired their virus through injecting drug use behaviour (sharing needles/syringes and other injecting paraphernalia) and the majority of these were former injectors who remained undiagnosed. [4] It was estimated that only 20% of the 38,000 chronically infected individuals had ever been in specialist care and only 5% had received a course of antiviral therapy which i) has been deemed cost effective by the National Institute for Health and Clinical Excellence (NICE) and Quality Improvement Scotland (QIS), [5,6] ii) achieves sustained viral clearance in 50-60% of instances [6-8] and iii) is likely to have a major impact in reducing the rate of Hepatitis C disease progression (naturally, 5-15% of carriers develop cirrhosis within 20 years).[9] As at December 2006, HPS estimated that around 2,100 Hepatitis C infected persons were living with cirrhosis and that 1,000-1,500 injecting drug users (IDUs) were becoming infected annually. [2]

Following an extensive consultation in 2005, the Health Minister and Chief Medical Officer launched Scotland's Action Plan for Hepatitis C in September 2006. [10]

Its aims are:

- To prevent the spread of Hepatitis C particularly among IDUs.
- To diagnose Hepatitis C infected persons, particularly those who would most benefit from treatment.
- To ensure that those infected receive optimal treatment, care and support.

The Plan is a two-phased one:

## Action Plan Phase I: generating the evidence base for the Phase II Actions

Phase I, undertaken during September 2006 to March 2008, involved increasing awareness about Hepatitis C among professionals and gathering evidence through numerous surveys and other investigations to inform proposals for the development of Hepatitis C services during Phase II. Additionally, NHS Boards received £2 million in each of 2006/07 and 2007/08 to support a limited amount of service development during this period.

Phase I was co-ordinated by HPS. An Action Plan Co-ordinating Group (APCG), comprising representatives of key stakeholder groups (Appendix 1), oversaw the implementation of the Action Plan; the APCG was supported by Working Groups, corresponding to the three areas of i) Testing, Treatment, Care and Support, ii) Prevention, and iii) Education, Training and Awareness-raising (Appendices 2,3,4), and an Implementation Group/Project Team (Appendix 5), and was accountable to the Scottish Government Public Health & Wellbeing Directorate.

Nearly all of the 41 Phase I actions have been delivered and only one – the piloting of an in-prison needle and syringe exchange scheme – has been rescheduled to be implemented during Phase II. A report on Phase I progress was published in December 2007. [11]

Under the auspices of the APCG, the actions for Phase II were generated by its three working groups. Each, during the first half of 2007, oversaw the implementation of actions involving the generation of evidence; during the second half, they translated the evidence into proposed key issues and actions. Initial proposals were shared with i) the APCG, ii) NHS Board Hepatitis C Executive Leads, appointed during Phase I (Appendix 6) and, iii) nearly 200 stakeholders at a consultation event held in the Royal College of Physicians, Edinburgh; issues, evidence and proposed actions were presented to the stakeholders who indicated their approval/disapproval through a digital voting system, and via email and proforma correspondence after the event.

The working groups modified the actions in accordance with the findings of the consultation and, by early 2008, they were approved by the APCG. Approval, by the Minister for Public Health, was given for the Phase II Plan to be launched on World Hepatitis Day, May 19, 2008.

## Action Plan Phase II: improving services

Phase II covers the three years 2008/09, 2009/10 and 2010/11. For each of its actions the following have been identified: desired outcome(s), performance measures to gauge progress in achieving the desired outcome(s), timescales, the lead organisation(s) accountable for delivering the action and key network(s) to support the lead organisation(s) (Appendix 7).

The actions are categorised into those for i) Testing, Treatment, Care and Support, ii) Prevention, iii) Information Generating and iv) Co-ordination activities. Generally, they are high level in nature, allowing NHS Boards, in particular, the freedom to develop services in the context of their particular circumstances regarding existing arrangements for Hepatitis C service provision and the epidemiology of infection in their area. Guidelines, standards and local/national networks will ensure that approaches taken are effective, efficient and, where appropriate, consistent.

A multi-disciplinary approach, manifested by the establishment of several local and national networks comprising representatives from all relevant disciplines and organisations, will be adopted. A considerable emphasis is placed on co-ordination and monitoring to ensure that organisations, accountable to the Scottish Government, deliver actions effectively, efficiently and to time.

The Action Plan is designed to improve all services applicable to the prevention of, and diagnosis and care of persons with, Hepatitis C, ranging from those that provide education to young people in schools about the dangers of injecting drug use and Hepatitis C to the treatment of infected

persons with antiviral drugs and the associated social support required to support them and their families through what, often, is a challenging journey.

In the context of Hepatitis C being a condition which affects, mainly, people who are vulnerable and marginalised, the Action Plan recognises the crucial role of the voluntary and local authority sectors in providing education, training and social support services and the huge opportunity for Hepatitis C-related prevention, diagnosis and treatment in Scotland's prisons.

The timescales for actions are interdependent to ensure that service development is undertaken in an integrated manner; for example, awareness campaigns to promote Hepatitis C testing will only be undertaken (in 2009) once the workforce has been trained and Testing, Treatment, Care and Support services required to manage the resulting increased demand for these, have been established.

### *Resources*

Services will be planned and arranged in year one (2008/09), fully activated in year two (2009/10) and further developed in year three (2010/11). Accordingly, of £43.2m made available for the Plan over the three years, £5.6m (13%), £16.3m (38%), and £21.3m (49%), respectively, is being allocated for the first, second and third years. A total of £36.7m (85%) of the £43.2m, will be distributed among the 14 NHS Boards for the development of Prevention (£8m) and Testing/Treatment/Care and Support (£28.7m) services. In recognition of the importance of social support for people infected with, and affected by, Hepatitis C, approximately £3 million of this latter allocation is being dedicated to agencies, including Non Governmental Organisations (NGOs), providing such services; these include the UK Hepatitis C Resource Centre which has been, and continues to be, instrumental in the development and implementation of the Action Plan. A new funding formula, accounting for the size of the i) overall, ii) IDU, iii) Hepatitis C infected and iv) prison population (reflecting the responsibility of Boards with prisons to ensure that inmates have access to NHS Hepatitis C services) in each NHS Board area, was adopted to distribute funding equitably.

The Plan's three-year duration aligns with the Scottish Government spending review cycle; it is appreciated, however, that in 2011/12 and beyond, some of the Phase II actions will no longer apply, some will need to be maintained, and some, further developed. The Scottish Government, continuously, will review the progress made with, and performance of, the Action Plan, and decisions regarding post-Phase II arrangements will be made in 2010/11. It is anticipated that, by 2011, actions will have led to considerable increases in the numbers of persons diagnosed with Hepatitis C and the numbers of infected persons having cleared their virus through antiviral therapy, and early signs that the numbers of transmissions of Hepatitis C among IDUs are starting to decline.

## The Presentation of the Action Plan

The following sections on Testing, Treatment, Care and Support, Prevention, and Information Generating, provide detail on i) how evidence was attained to generate the actions, ii) examples of evidence, iii) the main issues stemming from the evidence, iv) the actions designed to address the issues and, v) the desired outcomes to be generated by the actions. The final section outlines a framework for the co-ordination of the Action Plan nationally, by HPS, and locally, by the NHS Boards. All of the above is referenced in a summary table which, for each action, also provides information on the lead organisation(s), the supporting networks and performance indicators (Appendix 7).

The evidence to support the issues and actions is referenced and can be accessed via the Hepatitis C Scotland website (www.hepcscotland.co.uk). Note that, unless specifically stated, evidence applies to Scotland as a whole. Detailed NHS Board specific information, where available, can be obtained from HPS (Email: HCVActionPlan@hps.scot.nhs.uk).

## Testing, Treatment, Care and Support

Two Working Groups – the Testing, Treatment, Care and Support Group and the Education, Training and Awareness-raising Group – undertook activities to gather robust data to inform the development and expansion of Hepatitis C Testing, Treatment, Care and Support services during 2008 and beyond. The key objectives were to describe the existing provision of Hepatitis C testing, treatment, care and support services and the training for professionals responsible for delivering such services across Scotland, and to identify gaps and issues relating to service/training provision.

The approach adopted to gather the evidence, involved self-administered questionnaire surveys and face-to-face interviews with service providers, the analysis of existing data held on laboratory and clinical databases, examining scientific literature and undertaking analytical studies to estimate the current and future clinical and financial burden of Hepatitis C related disease in Scotland (http://hepccentre.org.uk/Search.aspx?S=Service).

The following is presented: background information, a summary of the key findings and, for each key issue, evidence supporting the proposed action(s) to be taken and desired outcomes.

### Background Information

In 2006:

- 60,000 Hepatitis C antibody tests were undertaken, [12]
- 1,500 new diagnoses were made (2.5%), [12,13]
- an estimated 250 and 110 Hepatitis C infected persons, respectively, developed cirrhosis and liver failure, [3,14]
- 25%, 21% and 15% of testing, was performed in the general practice, hospital in-patient and hospital out-patient settings, respectively, [12]
- 4,000 patients attended 16 Hepatitis C Treatment Centres, [3]
- 450 patients were initiated on Hepatitis C antiviral therapy, [3]
- the Hepatitis C Treatment workforce comprised 12.5 Whole Time Equivalent (WTE) nurses and 4.5 WTE consultants, equating to one WTE nurse/300 patients and one WTE consultant/900 patients accessing specialist services. [3]

To 2006:

- of an estimated 38,000 living persons chronically infected with Hepatitis C, 14,500 had been diagnosed, 8,000 had ever attended specialist clinical services for chronic Hepatitis C and around 2,000 had received antiviral therapy, [3]
- an estimated 2,100 Hepatitis C infected persons had progressed to, and were living with, cirrhosis. [3, 14]

### Summary of Key Findings

- In recent years, very considerable progress in developing high quality services for Hepatitis C infected persons in Scotland, has been made; there are, however, several issues which need to be addressed.
- Insufficient numbers of infected persons, particularly former IDUs, are diagnosed.
- Widespread variations in the clinical management of Hepatitis C infected persons exist.
- The training of the Hepatitis workforce is substandard.

- There is a lack of integration among primary care, specialist, addiction, prison and social care services, resulting in many Hepatitis C infected persons failing to complete a successful passage through the diagnostic, referral, treatment and care pathway.
- Insufficient numbers of infected persons are being administered antiviral treatment, and resources, particularly for specialist clinical management and social care, including the support of persons journeying through the patient pathway, are inadequate.

All of the above findings are inter-related.

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## ISSUE

Widespread variations in the approach to the clinical management and social care of Hepatitis C infected persons exist across Scotland. Only two NHS Boards in Scotland have a Managed Care Network (MCN) for Hepatitis C and although Guidelines on the clinical management of persons with Hepatitis C exist, formal standards do not.

### Evidence

Variations exist:

- among General Practitioners (GPs) in their approach to identifying people at risk of Hepatitis C, and thus testing individuals for Hepatitis C, and referring people to Hepatitis C clinics; more than 80% don't ask their patients about risk factors and about 80% refer, to specialist centres, persons who have evidence of having spontaneously cleared their infection, [15]
- among laboratories in the way they test for Hepatitis C and report results to clinicians, [12]
- among Hepatitis C clinics in the proportions of their (first appointment) referred patients who fail to attend (20-70%) and in the ways they follow-up such non attendees, [3,16]
- among Hepatitis C clinics in the approaches they take to clinically manage their patients; approximately half prioritise patients for therapy and between 50-92% of new clinic attendees with chronic infection are not administered antiviral therapy within three years of first attendance for various reasons including patients dying, failing to re-attend, continuing to inject drugs and/or having a chaotic lifestyle, and having other medical/psychiatric contraindications. [3]

### Actions

- Each NHS Board will have, or be affiliated to, an MCN for Hepatitis C; this Network will comprise representatives of relevant specialists in healthcare and other stakeholder groups including those for the prison service, local authority, social work, the voluntary sector, mental health, addictions, and people living with and affected by Hepatitis C. The Network will be guided in its practice through the use of "Care" Guidelines, prepared by the Hepatitis C Action Plan's Testing, Treatment, Care and Support Working Group (http://www.hepcscotland.co.uk/pdfs/guidelines-for-hepatitis-c-care-networks.pdf )[17] and the Scottish Intercollegiate Guidelines Network (SIGN) guidelines on the management of Hepatitis C (**Action 1**). [6]
- NHS Quality Improvement Scotland (QIS) will develop Standards for Hepatitis C testing and the treatment, care and social support of persons with Hepatitis C infection (**Action 2**).

### Outcome

These actions will ensure that approaches to the diagnosis and management of Hepatitis C infected persons throughout Scotland are highly effective and, where appropriate, consistent.

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## ISSUE

The training of the Hepatitis C workforce is ad hoc and often sub-standard with no alignment to quality frameworks.

### Evidence

- Training is delivered on an informal/ad hoc basis; no national or strategic approaches to training exist. [18]
- Training is not aligned to a National Quality Framework and around one-third of training initiatives are never evaluated. [18]
- Major gaps in training across the Hepatitis C workforce, excluding Hepatitis C specialist NHS staff, are evident. [18]
- Few dedicated funding streams for Hepatitis C training of the workforce were identified; many training providers reported difficulties in identifying resources for training. [18]

### Actions

- A National Hepatitis C Learning and Workforce Development Framework will be developed (**Action 3**).
- NHS Boards, working with their partners, will identify a Hepatitis C Workforce Development Lead, review the learning and development needs of the Hepatitis C Workforce, and implement a co-ordinated approach to Hepatitis C Workforce Development consistent with the National Hepatitis C Learning and Workforce Development Framework (**Action 4**).
- Awareness-raising campaigns and communications initiatives will continue to be developed, implemented and evaluated to meet the information and education needs of a range of professional audiences (including those responsible for the delivery of prevention services) (**Action 5**).

### Outcome

These actions will ensure that Scotland's Hepatitis C Workforce in its entirety is knowledgeable, skilled and confident.

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## ISSUE

Insufficient numbers of Hepatitis C infected persons, including prisoners, receive antiviral therapy.

### Evidence

- A total of 5% and 14%, respectively, of all (38,000) and diagnosed (14,500) chronically infected persons have been administered antiviral therapy. [3]
- Around 450 persons/year are being initiated on therapy – a total which should be considered in the context of i) the figures above, ii) annual numbers of Hepatitis C-

related liver deaths having doubled from 49 in 1999 to 95 in 2005,[19] and iii) an estimated 1,000-1,500 new infections occurring annually among IDUs. [3]

- It is estimated that if 2,000 persons/year received antiviral therapy, over the next two decades 2,500 and 2,700 cases, respectively, of Hepatitis C-related cirrhosis without liver failure and cirrhosis with liver failure would be prevented. [3, 20]
- Antiviral therapy for all infected individuals, excluding those who have progressed to very severe liver disease, has been deemed highly cost-effective by NICE and QIS. [5,6]
- Of the 450 persons initiated on therapy during 2006, approximately 30 were prison inmates; 12 of the 30 received their treatment inside prison. [3]
- In the mid 1990s, approximately 24% of Scotland's prison inmates were infected with Hepatitis C. [21]

### Actions

- Testing, Treatment, Care and Support services within each NHS Board will be developed to increase the number of persons undergoing therapy in Scotland from 450/year to 500 in 2008/09, 1,000 in 2009/10, 1,500 in 2010/11 and at least, 2,000/year thereafter (**Action 6**).
- Service Level Agreements/Memoranda of Understanding between NHS Boards and the Scottish Prison Service (SPS) to promote the treatment of Hepatitis C infected inmates in prisons will be developed in the context of the SPS Blood Borne Virus (BBV) strategy (**Action 7**).

### Outcome

These actions will increase the numbers of infected persons who clear their infection and thus reduce the numbers of infected persons who develop severe Hepatitis C-related liver disease.

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## ISSUE

In many parts of Scotland there are insufficient links between social care, addiction, mental health services and specialist services for Hepatitis C treatment. It is not possible to manage and treat Hepatitis C infected persons without considering their social care, and any drug/alcohol problem needs.

There is a paucity of local authority (social care) involvement with Hepatitis C infected persons across Scotland.

### Evidence

- More than half of Scotland's main Hepatitis C treatment centres have no outward referral links with mental health and addiction services and only one-quarter have outward referral links with social care services. [3, 16]
- Focus Group sessions and interviews with service providers generated a clear and consistent message that strong links involving Hepatitis C treatment, mental health, addiction and social care services are vital in ensuring a successful passage for the infected individual through the pathway from diagnosis to antiviral treatment and after care. [3, 22]

### Actions

- For each NHS Board a formal plan, indicating how it has integrated or will integrate appropriate elements of Hepatitis C specialist treatment services into those for social

care, mental health and addiction in local authority, voluntary sector, primary care and secondary care settings, will be developed and implemented (**Action 8**).
- Each local authority will identify a strategic and operational Lead for Hepatitis C infection (**Action 9**).

### Outcome

An integrated approach to the management of Hepatitis C infected persons involving Hepatitis C treatment, social care, and mental health/addiction will be fostered.

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## ISSUE

The majority of persons chronically infected with Hepatitis C remain undiagnosed and many of those diagnosed fail to reach and stay within specialist care services. There are widespread variations in testing practice in the community setting. The uptake of Hepatitis C testing among past and current IDUs is sub-optimal following test offer.

### Evidence

- Of an estimated 38,000 living persons, chronically infected with Hepatitis C, in Scotland, 14,500 have been diagnosed; the great majority of those undiagnosed are persons who have stopped injecting drugs but an appreciable minority (2,000-3,000) have never injected. [3]
- Approximately 95% of GPs in Scotland did not diagnose a single case of Hepatitis C during 2006. [3]
- Approximately 80% of GPs in Scotland do not systematically seek out risk factors for Hepatitis C among their practice populations. [3, 15]
- Most needle/syringe exchange facilities in Scotland do not provide on-site Hepatitis C testing services. [23]
- GPs and other professionals involved in the provision of Hepatitis C services agree that Hepatitis C testing should be promoted in the General Practice and other primary care settings, particularly those for IDUs. [15, 22]
- Studies undertaken in Glasgow confirmed that a targeted approach to Hepatitis C testing in the General Practice setting – one which focuses on persons aged over 30 who have ever injected drugs – generates a high test uptake and yield of positivity among persons who have discontinued or are near to discontinuing drug injecting; such individuals are more likely than recent onset injectors to be ready and eligible to receive antiviral therapy. [24, 25]
- GPs and other service providers indicated that difficulties in taking blood for Hepatitis C testing from persons who had injected drugs and the often long interval between blood taking and a result being available, were barriers to testing uptake and result disclosure; IDUs, not infrequently, fail to return to learn their Hepatitis C status. [3, 21]
- Approximately 50% of newly diagnosed infected persons, referred to specialist clinics, fail to attend their appointment. [3, 16]
- A review of evaluations of Hepatitis C public awareness-raising campaigns worldwide revealed that few had been undertaken; those that had been performed identified strengths and weaknesses - findings which should inform future Scottish campaigns. [26]

### Actions

- NHS Boards will work with Community Health Partnerships (CHPs) to develop and implement a plan, incorporating innovative approaches, to improve Hepatitis C testing and referral activities by GPs and other community setting practitioners (**Action 10**).

- An awareness-raising campaign, to promote Hepatitis C testing among those at risk of being infected, will be implemented and evaluated (**Action 11**).
- A programme of work to evaluate different approaches to Hepatitis C testing/body fluid sampling (e.g. near patient testing/use of saliva and dried blood spots) will be undertaken (**Action 12**).

## Outcome

These actions will reduce the proportion of Hepatitis C infected individuals who are undiagnosed.

# Prevention

Two groups – the Prevention Group and Education, Training and Awareness-raising Group – undertook activities to gather robust data to inform the development and expansion of Hepatitis C Prevention Services during 2008 and beyond. The scope of the work was confined to the prevention of Hepatitis C among IDUs through, in the main, the provision of injection equipment because i) the great majority of Hepatitis C infections occur as a consequence of drug injecting practices and, ii) this intervention type, unlike, for example, methadone maintenance, was and is designed principally to prevent the transmission of BBVs among IDUs. Considerable consideration, however, was given to measures aimed at preventing the initiation, and promoting the discontinuation, of drug injecting.

The key objectives were to examine i) the effectiveness of injection equipment provision in preventing the transmission of Hepatitis C among IDUs, ii) the current provision of injection equipment to IDUs in Scotland, and iii) existing policy on injection equipment provision to identify gaps in, and issues relating to, existing services.

The approaches adopted to examine evidence involved undertaking systematic reviews of the scientific literature and reviews of existing reports, such as that for Scotland's National Needle Exchange Survey, and telephone interviews in the context of reviewing current teaching on Hepatitis C in Scotland's educational establishments.

The following is presented: background information, a summary of the key findings and, for each key issue, evidence supporting the proposed action(s) to be taken and desired outcomes.

## Background Information

- The estimated number of current IDUs in Scotland in 2003 was within the range 17,700-20,300. [27]
- It is estimated that 90% of Scotland's Hepatitis C infected population has injected drugs. [4]
- In Glasgow, the incidence of Hepatitis C is steady at 20-30 infections per 100 person years of injecting. [4]
- Approximately 30% and 40% of IDUs in Scotland, in contact with drug treatment or harm reduction services, report having recently injected with a needle/syringe and other injecting paraphernalia used previously by someone else, respectively. [28]
- As at mid-2005, 188 needle/syringe exchange outlets, of which 136 were pharmacy based, were operating. Of 43 specialist, non-pharmacy facilities, 22 offered mobile/outreach services. [23]
- At least 3.5 million needles/syringes were distributed to IDUs during April 2004-March 2005. [23]
- The incidence of Hepatitis C infection among persons who do not inject drugs is low and the scope for preventing Hepatitis C infection among non-injectors is very limited; for example, it is estimated that around 10 babies, born to infected mothers in Scotland, are infected annually [31] but, currently, no interventions, such as antiviral therapy during pregnancy and caesarean section, have been shown to be both safe and effective. [30]
- Measures to prevent people contracting Hepatitis C through blood or blood product transfusion are highly protective. Other interventions designed to protect the public from Hepatitis C include the exclusion of known infected healthcare workers from operating on patients [29] and the recent licensing of tattoo parlours in Scotland; [32, 33] in these two contexts, transmissions in Scotland have not been identified but it should be appreciated that instances of transmission are difficult to identify because Hepatitis C rarely presents as an acute illness.

## Summary of Key Findings

- Since the late 1980s, services providing needles/syringes to IDUs have been developed; these, likely, have made a major contribution to the prevention of HIV transmission among IDUs in Scotland. In the context of the more infectious and more longstanding (in terms of prevalence) Hepatitis C virus, however, there are many issues which need to be addressed.
- Widespread variations in the provision of injection equipment and educational initiatives for IDUs to prevent Hepatitis C transmission due to gaps in co-ordination and guidance, exist; there remains, however, uncertainty about the relationship between such variations and the incidence/prevalence of Hepatitis C among IDUs.
- A high frequency of injection equipment sharing and incidence of Hepatitis C among IDUs is observed.
- Opportunities to evaluate novel approaches to injection equipment provision in community and prison settings, exist.
- A dearth of Hepatitis C information provision for young people in educational settings is evident.

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## ISSUE

Widespread variations in the provision and uptake of injection equipment and educational initiatives to prevent Hepatitis C transmission exist throughout Scotland. Many NHS Boards do not have formal networks to facilitate the prevention of Hepatitis C. Other than guidelines on the number of sets of needles/syringes that can be given to IDUs, comprehensive National Guidelines for services providing injection equipment do not exist.

### Evidence

- The estimated numbers of needles/syringes distributed to each IDU during 2005 ranged from 57-479 among Scotland's Drug Action Team areas. [23]
- The shortfall in sets of needles/syringes that need to be distributed to IDUs, if the number of such sets is to correspond with the number of injecting events, is estimated to be several million/year.[23,27]
- Major variations in any access to injection paraphernalia other than needles/syringes (filters, stericups/cookers and sterile water) exist across Scotland. [23, 34]
- Based on work undertaken in Glasgow, there is evidence of a direct relationship between injection equipment sharing and poorer access (distance) to a needle/syringe exchange facility. [35]
- Most injection equipment facilities do not provide evening or weekend access and only one service in Scotland is open 24/7. [23]
- Experts are of the opinion that some, particularly recent-onset, IDUs do not frequent existing injection equipment provision services because they feel uncomfortable about disclosing their behaviour to individuals who they perceive to be disapproving of them.
- Adherence to official guidelines on the numbers of needles/syringes to be distributed to IDUs is inconsistent among services providing injection equipment. [23]
- Most injection equipment provision services do not provide an evening or weekend service. Only one service is open 24/7. [23]

### Actions

- Each NHS Board will have, or be affiliated to, a Network covering the Prevention of Hepatitis C and comprising representatives of all stakeholder sectors. Guidance regarding Network membership and Terms of Reference for the Hepatitis C component

will be established. Each NHS Board will identify a Hepatitis C Prevention Lead (**Action 13**).

- National Guidelines for services providing injection equipment to IDUs will be developed. A Guideline Development Group will be established (**Action 14**).

### Outcome

These actions will ensure that approaches to the provision of injection equipment to IDUs throughout Scotland are highly effective and, where appropriate, consistent.

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## ISSUE

The re-use/sharing of injection equipment among IDUs is still highly prevalent and Hepatitis C transmission among IDUs throughout Scotland is very common.

### Evidence

- It is estimated that well over 90% of new Hepatitis C infections in Scotland occur in people who have injected drugs; [4] small numbers of infections may occur in persons who have never injected drugs but usually they are indirectly associated with injecting drug use: for example, babies born to infected mothers who have injected drugs [29] and sexual partners of infected injectors. [36]
- Around 30% and 40% of IDUs in Scotland, in contact with drug treatment or harm reduction services, report having injected with a needle/syringe and other injecting paraphernalia, used before by someone else, during the previous month, respectively. [28]
- Although there is some evidence of a decline in the frequency of injection equipment sharing during the last ten years, its extent is minimal. [28]
- The incidence of Hepatitis C infection among IDUs in Glasgow remains extremely high at 20-30 per 100 person years of injecting. [4]
- It is estimated that between 1,000 and 1,500 IDUs in Scotland are infected annually. [2]
- A systematic review of the literature did not identify definitive evidence of harm reduction interventions, including needle/syringe exchange, educational initiatives and Hepatitis C testing, having had an impact on Hepatitis C transmission among IDUs but the absence of such evidence does not necessarily mean absence of effect as hardly any robustly designed studies have been undertaken anywhere. Nevertheless, studies have demonstrated that the provision of injection equipment is associated with reductions in numbers of needle/syringe sharing episodes. [37]
- Scottish investigations, the findings of which have been published in reputable scientific journals, provide evidence that harm reduction measures – principally needle/syringe exchange and methadone maintenance therapy – may have led to considerable reductions in Hepatitis C transmission among IDUs. [38-40] It is estimated that, in Glasgow during 1988-2000, such interventions may have prevented 4,500 infections. [41]
- Further, the prevalence of Hepatitis C among young IDUs (aged less than 25) in Scotland's major cities declined from 60-90% in the late 1980s/early 1990s to 15-40% in the late 1990s/early 2000s – a trend which coincides with the expansion of harm reduction services. [40]
- An ethnographic study found that the storage of needles/syringes by IDUs for re-use was common – a practice which could result in the inadvertent sharing of such equipment. [42]

### Actions

- Services providing injection equipment (needles/syringes and other injection paraphernalia) will be improved in accordance with the Guidelines referred to in action 14 above. Improvements will be made in terms of the i) quantity (increasing access and uptake of equipment through innovative, including outreach, approaches) ii) quality (e.g. the colour coding of equipment to avoid sharing) and, iii) nature (e.g. the provision of equipment other than needles/syringes), of provision (**Action 15**).
- Educational interventions aimed at vulnerable individuals, IDUs and those at risk of starting to inject will be designed and implemented to highlight how Hepatitis C transmission can be prevented. Particular attention should be given to initiatives aimed at identifying existing and newly diagnosed IDUs with Hepatitis C to prevent the onward transmission of infection (**Action 16**).

### Outcome

These actions, hopefully, will lead to reductions in injection equipment sharing and Hepatitis C transmission among IDUs; if such reductions are achieved it may be difficult to attribute them, with certainty, to the specific interventions as described above.

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## ISSUE

IDUs who continue to inject drugs in prison do not have access to injection equipment in that setting.

### Evidence

- Although methadone therapy for prison inmates in Scotland has become increasingly available in recent years, it is estimated that between 200 and 300 inmates inject drugs in prison at least once/month. [43]
- Inmates who inject drugs in prison do so, usually, with unsterile, often “home-made”, injection equipment. [44]
- A study, undertaken in Shotts Prison in 1999/2000, demonstrated an incidence of 12 infections per 100 person years of incarceration among inmates who had ever injected drugs during their lives. [45]
- Needle/syringe exchange schemes have been implemented in selected prisons in some European countries, particularly Spain, Germany and Switzerland, but not the UK; evaluations, undertaken in some instances, demonstrated acceptability of the intervention to inmates/staff and an association between in-prison provision of needles/syringes and a reduction in needle/syringe sharing frequency. None of the evaluations had the power or the appropriate design to demonstrate effectiveness, apropos reducing Hepatitis C transmission. [37]

### Actions

- An in-prison needle/syringe exchange initiative will be piloted as one of a range of harm reduction measures to reduce the transmission of Hepatitis C (**Action 17**).

### Outcome

This action will demonstrate the acceptability, to users and prison officers, and use of an in-prison service providing injection equipment.

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## ISSUE

Persons in school and further education settings receive little, if any, education about Hepatitis C.

### Evidence

- The majority of secondary schools deliver little or no teaching on Hepatitis C within either their Drug or Sex Education Programmes. Only half of secondary schools provide education on injecting drugs. [46]
- In the primary school setting, references to Hepatitis C are not made. [46]
- In the further education college setting, there is little evidence of initiatives relating to the provision of information on Hepatitis C. [46]
- Experts are of the opinion that education on Hepatitis C, in the context of other BBVs such as HIV, should be provided to young people under the age of 25 in the above settings but also in other community settings for vulnerable young people (e.g. juvenile offender settings) who may miss out on such education if it was provided in educational establishments only. [46]

### Actions

- Hepatitis C guidance and educational support materials (within the context of BBVs/drugs misuse) will be developed, disseminated and evaluated to raise awareness among young people in school, further education and community settings, and other settings which support vulnerable young people. Staff/peer group training initiatives will facilitate the implementation of this action (**Action 18**).

### Outcome

This action will increase awareness and knowledge of Hepatitis C among young people in Scotland.

## Information Generating Initiatives to Monitor the Performance of Actions

It is essential that the performance of actions to improve the prevention, diagnosis, treatment, care and support services to i) reduce the numbers of people becoming infected with Hepatitis C, ii) reduce the proportion of infected people who are undiagnosed and, iii) increase the numbers of infected people who clear their virus as a consequence of antiviral treatment, is monitored closely. All three Phase I Working Groups – the Prevention Group, the Testing, Treatment, Care and Support Group and the Education, Training and Awareness-raising Group – considered what Information Generating Initiatives (IGIs) would be required in the context of their proposed actions; this was achieved by reviewing existing systems to identify if these needed further development or if completely new IGIs were required.

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### ISSUE

Clinical data to monitor the performance of actions 6 and 7 are required.

#### Evidence

- Some sources of information such as the Scottish Hepatitis C Diagnosis Database – providing data on numbers and demographic/risk characteristics of persons diagnosed with Hepatitis C – are well established. [13]
- The bulk of funding for Phase II of the Action Plan will be spent on improving treatment, care and support services so that the numbers of persons receiving antiviral therapy will increase from 450 in 2006 to 1,500 by 2010/11; the drug costs of a course of antiviral therapy are, on average, £8,000. It is essential that robust clinical data to monitor, for example, the numbers of persons offered, receiving and responding to therapy in all major treatment centres, are available.
- Since 2004, the Scottish Government has funded the development of local clinical databases, the data from some of which informed key Phase II actions. The current system, however, is relatively rudimentary. In the context of a very considerable increase in the numbers of infected persons to be managed in specialist treatment centres over the Phase II period and beyond, a Generic Clinical System for Hepatitis C – one that not only provides monitoring data but facilitates patients' management and conforms with Scotland's e-Health requirements – is needed.

#### Actions

- The further development of the National Hepatitis C Clinical Database, including the establishment of a Generic Clinical System for Hepatitis C, will be undertaken (**Action 19**).

#### Outcome

This action will ensure that measures to improve treatment, care and support services for Hepatitis C infected individuals, and thus reduce their chances of progressing to severe Hepatitis C-related disease, are evaluated effectively.

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### ISSUE

Data to monitor the performance of actions 10 and 11 are required.

#### Evidence

- In 2009, public awareness campaigns to promote Hepatitis C testing among persons at risk of infection will be implemented. It is important that the performance of the campaigns regarding numbers of people undertaking a Hepatitis C test and the yield of detected infections is monitored as a measure of how appropriately testees have self-selected.
- A National Hepatitis C Diagnosis Database, involving the reporting of Hepatitis C positive diagnoses by laboratories to HPS, exists but, currently, data on all persons undergoing testing, regardless of test result, are unavailable. Accordingly, a system to capture such data is required.

#### Actions

- The development of a surveillance system to monitor Hepatitis C testing practice in Scotland will be undertaken (**Action 20**).

#### Outcome

This action will ensure that awareness campaigns aimed at reducing the proportion of infected persons who are undiagnosed are evaluated effectively.

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### ISSUE

Data to monitor the performance of actions 14-16 are required.

#### Evidence

- A considerable amount of funding is being allocated for i) the improvement of services providing injection equipment to IDUs, ii) the education of this group and individuals at risk of starting to inject drugs and, iii) the generation of guidelines on injection equipment provision.
- Virtually no robust studies have been undertaken anywhere to ascertain the effectiveness of harm reduction interventions at preventing Hepatitis C transmission among IDUs. [34] The reasons for this are multiple and include: the complexity of designing such studies (particularly experimental ones involving intervention and control populations); the ethics of performing such studies in the context of the interventions already being fully or partially introduced; and, the expense of such studies.
- With the implementation of Phase II of the Action Plan there is a unique opportunity to gauge the impact of a package of major interventions on injection equipment uptake and sharing, and on Hepatitis C transmission among IDUs, by examining these measures before and after the implementation of the package in 2009. The interventions involve the generation of guidelines on injection equipment provision, the improvement of such provision in terms of quantity, quality and nature of service, and the development of more and better educational initiatives for IDUs and persons at risk of commencing injecting.
- Despite injection equipment having been made available to IDUs in Scotland over the last 20 years, no systematic approach to collecting data on the provision and uptake of such equipment exists.
- If the effectiveness of interventions is to be fully evaluated, it is essential that data on the incidence of Hepatitis C infection among IDUs throughout Scotland are collected.

- Studies, undertaken in Scotland [4] and elsewhere, demonstrate that measures of Hepatitis C incidence among IDUs can be generated through testing them for Hepatitis C and i) relating the result to the date of injecting drug use commencement and the age of the person and, ii) undertaking, on samples, laboratory tests which identify individuals who have just recently become infected.

### Actions

- The development of a data collection system to monitor the provision of injection equipment in Scotland will be undertaken (**Action 21**).
- Annual surveys of Hepatitis C prevalence and incidence among IDUs across Scotland will be performed (**Action 22**).

### Outcome

These actions will ensure that the package of interventions designed to increase uptake and reduce sharing of injection equipment, and reduce Hepatitis C transmission, among IDUs is evaluated effectively.

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## ISSUE

If the performance of actions involving the development of prevention, diagnosis, treatment, care and support services in the prison setting is to be gauged, it is important that the proportion of Scotland's prison population who are Hepatitis C infected, the proportion of this group who are undiagnosed and the incidence of Hepatitis C transmission among prison inmates, is understood.

Also, if a sound understanding of the Hepatitis C diagnosis, treatment, care and support needs of i) children and ii) persons originating from Pakistan (and, possibly, other South Asian countries) – populations about whom little is known, apropos the proportions infected with Hepatitis C – is to be achieved, it is essential that prevalence studies on these groups are undertaken.

### Evidence

- The most recent series of Hepatitis C prevalence studies in Scotland's prisons were undertaken in the mid 1990s; inmates of five adult prisons were surveyed. Overall, Hepatitis C antibody prevalence was 24%. [21]
- The only UK in-prison Hepatitis C incidence study was undertaken in Shotts Prison during 1999/2000; the incidence of Hepatitis C among inmates who had ever injected drugs was 12 per 100 person years of incarceration. [45]
- Since the late 1990s, Scotland's prison population demographics have changed (e.g. more prisoners) and large numbers of in-prison methadone therapy slots for drug users have become available.
- No major studies to determine the prevalence of Hepatitis C among children in the UK have been performed. A pilot study of children, averaging five years of age, who attended the General Anaesthetic Department of the Glasgow Dental Hospital and School in 2002, revealed that 2 of 70 were infected and that performing such a study in this setting was ethical and acceptable to parents and children. [47]
- In Glasgow, where the great majority of Scotland's 32,000 Pakistani population reside, [48] Pakistani males, over the age of 50, have a tenfold greater chance of having been diagnosed Hepatitis C positive than other men belonging to the same age group. [49]
- Studies to determine the prevalence of Hepatitis C among first generation Pakistani populations in England are being conducted.
- The interest in knowing the prevalence of Hepatitis C among first generation Pakistanis stems from knowledge that the prevalence of Hepatitis C in Pakistan (4-7%) [50-52] is one

of the highest in the world and that around 320,000 Pakistani born individuals live in the UK. [53]

## Actions

- A survey of Hepatitis C prevalence and incidence among prisoners in Scotland will be undertaken (**Action 23**).
- Surveys to estimate the prevalence of Hepatitis C among i) children in Scotland and, ii) people in Scotland who have lived in Pakistan (and, possibly, other South Asian countries) will be undertaken (**Action 24**).

## Outcome

These actions will generate data to inform the needs of Hepatitis C infected prisoners, children and Pakistanis and will ascertain the effectiveness of measures to prevent the spread of Hepatitis C within the prison setting.

# Co-ordination

For Phase I of the Action Plan, co-ordination, management, governance and communication arrangements were established to ensure the effective implementation of actions; these actions, however, mostly involved awareness-raising initiatives among professionals concerned with the prevention of, and management of persons with, Hepatitis C, and the generation of evidence to inform Phase II of the Action Plan; further, only a modest amount of funding (£4 million) was made available to NHS Boards during the two-year period of the Plan (2006-08).

In contrast, Phase II actions are designed to dramatically improve prevention, diagnosis, treatment, care and support services for Hepatitis C throughout the country and are associated with an investment of approximately £43 million, over three years, the bulk of which will be allocated to NHS Boards. Accordingly, the existing Phase I co-ordination, management, governance and communication arrangements need to be reshaped to ensure the effective and timely delivery of Phase II actions.

In Phase I, the Action Plan Co-ordinating Group – supported by the three Working Groups for i) Testing, Treatment, Care and Support, ii) Prevention and, iii) Education, Training and Awareness-raising – was accountable to the Scottish Government for delivering the great majority of the actions, the most important of which was the generation of the Phase II Plan; in this respect, much of the work involved was strategic in terms of gathering and interpreting evidence and then making recommendations.

## Accountability and Reporting

The Phase II Plan, in contrast, mostly concerns the development of services by NHS Boards and other organisations, all of which will receive funding for this purpose. Accordingly, these lead organisations will be directly accountable to the Scottish Government.

Lead organisations will report progress on, and performance of, actions they are responsible for to the Scottish Government; to ensure this process is consistent and managed well, a Project Management approach (see Project Management below) will be employed. An Action Plan Governance Board (see Action Plan Governance Board below), run by HPS and comprising representatives of lead organisations, will facilitate/co-ordinate the reporting process. The Scottish Government will establish an Action Plan Advisory Board (see Action Plan Advisory Board below) to advise on progress with, and issues concerning, Action Plan delivery.

## Co-ordination: National and Local

HPS is responsible for co-ordinating the Action Plan nationally and the NHS Boards are responsible for its co-ordination locally.

### *Health Protection Scotland*

HPS, through National Services Scotland, its parent body, is responsible for co-ordinating the Action Plan nationally. National co-ordination involves the following key roles:

i) establishing and maintaining national networks to support NHS Boards and other organisations delivering different aspects of the Action Plan (see National Networks below),
ii) monitoring Action Plan progress and performance so that the plan is delivered in a timely, effective and efficient way; HPS will preside over an Action Plan Governance Board to facilitate this role (see Action Plan Governance Board below),

iii) communicating Action Plan progress to, and getting feedback from, stakeholders nationally (see National Communications below),
iv) employing a Project Management (see Project Management below) approach to undertake the above actions.

### *NHS Boards*

NHS Boards, through their Hepatitis C Executive Leads, are responsible for co-ordinating the Action Plan locally. Local co-ordination involves the following key roles:

i) establishing and maintaining local (though they could be regional) networks to support the planning, development and implementation of services (see Local Networks below),
ii) supporting HPS in monitoring Action Plan progress and performance,
iii) communicating Action Plan progress to, and getting feedback from, local/regional stakeholders and supporting HPS in doing the above at a national level,
iv) commissioning services,
v) employing a Project Management (see Project Management below) approach to undertake the above actions.

### *National Networks*

The following networks will be established so that experience, best practice and progress on the delivery of the Action Plan can be shared, and support, advice and guidance can be provided. Each of the networks will be instrumental in supporting lead organisations in the delivery of the Phase II actions they have responsibility for. The establishment of formal Networks does not preclude the formation of other networks; it is anticipated that much communication would be done via e-mail and that the balance between virtual and actual meetings would vary, depending on the demands on, and the requirements of, the Networks.

- Hepatitis C Executive Leads for NHS Boards and the SPS.
- MCN Clinical Leads/MCN Co-ordinators (i.e. either separate or combined).
- Hepatitis C Prevention Leads.
- Leads of national information generating initiatives to gauge the performance of actions.
- Leads of national education, training and awareness-raising actions (incorporating the workforce development leads).
- Leads of NGOs (primarily from the voluntary sector) with a major Hepatitis C remit.
- Local Authority Leads.

### *Local Networks*

NHS Boards will have, or be affiliated to, the following networks which will plan, develop, implement and audit services locally.

- Prevention Network incorporating Hepatitis C (a Hepatitis C Prevention Lead is to be appointed).
- A Hepatitis C Managed Care Network (led by a Clinical Lead and managed by a Co-ordinator).

### *Action Plan Governance Board*

An Action Plan Governance Board, comprising all Hepatitis C Executive Leads (including one for the SPS (new appointment)) and the Leads of each National Network (as above) will be

established to ensure that the Action Plan is being implemented in a timely, effective and efficient manner by monitoring operational progress (including spend), the performance of actions and identifying and addressing potential and evolving high-level problems. The Board will be presided over by HPS and will report its findings to the Scottish Government, representatives of which will attend in an observer capacity.

*Action Plan Advisory Board*

An Action Plan Advisory Board, from which the Scottish Government, can obtain advice and comment on progress, and issues concerning, the Hepatitis C Action Plan, will be established.

*National Communications*

National communication activities to keep stakeholders abreast of, and receive feedback on, Action Plan progress will include:

- the development of the existing Hepatitis C Scotland website, including stakeholder forum,
- the production of a Scottish Hepatitis C Action Plan Annual Report,
- a Scotland contribution to a UK Annual Report on Hepatitis C (with the Health Protection Agency), and
- the holding of an annual stakeholder meeting.

*Project Management*

A Project Management approach to co-ordinate the effective, efficient and timely delivery of the Action Plan, will be employed. This will involve establishing a Project Management Team at HPS and appointing Project Managers at NHS Board level; these Project Managers will not be accountable to the HPS Project Management Team but will work with, and be guided by, the Team to ensure a consistent and integrated approach to Action Plan co-ordination.

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## ISSUE

To ensure that the Action Plan is delivered efficiently, effectively, to timescales, and is governed appropriately, a range of actions at national and local levels will be implemented.

### Actions

*National*

- An Action Plan Advisory Board to advise and comment on issues concerning Action Plan progress and performance will be established (**Action 25**).
- National Networks to support NHS Boards and other organisations delivering the Action Plan will be established and maintained (**Action 26**).
- Action Plan progress and performance will be monitored; an Action Plan Governance Board will be established to facilitate this action (**Action 27**).
- Communications activities (e.g. Annual reports, website development and annual stakeholder conference) to keep stakeholders abreast of, and receive feedback on, Action Plan progress, will be undertaken (**Action 28**).
- To undertake the above actions, a Project Management approach will be employed (**Action 29**).

*Local*

- Local/Regional Networks to support the delivery of services will be established and maintained (**Action 30**).
- Local progress and performance will be monitored and support will be given to HPS and the Action Plan Governance Board to facilitate their national monitoring roles (**Action 31**).
- Communications activities to keep stakeholders abreast of, and receive feedback on, Action Plan progress will be undertaken; support will be provided for national communications initiatives (**Action 32**).
- Services will be commissioned (**Action 33**).
- To undertake the above actions, a Project Management approach will be employed (**Action 34**).

## Outcome

These actions will ensure the successful delivery of the Action Plan.

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# Appendix 1: Action Plan Co-ordinating Group membership

| Name | Position | Representing |
|---|---|---|
| Professor David Goldberg | Chair - Action Plan Co-ordinating Group | Health Protection Scotland |
| Mrs Ellen Carragher | Personal Assistant to Professor David Goldberg | |
| Dr Syed Ahmed | Chair | Hepatitis C Executive Leads |
| Dr John Dillon | Chair | Testing, Treatment, Care and Support Working Group |
| Mr George Howie | Chair | Education, Training and Awareness-raising Working Group |
| Professor Avril Taylor | Chair | Prevention Working Group |
| Ms Helena Bayler | Patient Representative | Patient Representative |
| Professor Sheila Bird | Biostatistician | MRC Biostatistics Unit, University of Cambridge |
| Mr Gareth Brown | Policy Manager | Scottish Government Public Health and Wellbeing Directorate |
| Dr Sheila Burns | Director | Hepatitis C Specialist Laboratories |
| Ms Jacqueline Campbell | Public Health Team Lead | Scottish Government Public Health and Wellbeing Directorate |
| Dr Bill Carman | Co-Chair | Viral Hepatitis Group |
| Professor Peter Donnelly | Deputy Chief Medical Officer | Scottish Government |
| Mr Fraser Fergusson | Director | National Services Scotland, Corporate Programme Office |
| Dr Ray Fox | Chair | Managed Care Network (Greater Glasgow and Clyde) |
| Dr Andrew Fraser | Director of Health and Care | Scottish Prison Service |
| Dr Charles Gore | Director | Hepatitis C Trust |
| Professor Peter Hayes | Co-Chair | Viral Hepatitis Group |
| Ms Carole Hunter | Lead Pharmacist | Glasgow Addiction Services |
| Dr Sharon Hutchinson | Senior Research Fellow | Analytical Advice, Health Protection Scotland |
| Ms Miriam King | Project Manager | Hepatitis C Action Plan Project |
| Mr David Liddell | Director | Scottish Drugs Forum |
| Dr John Logan | Chair | Scottish Blood Borne Virus and Sexually Transmitted Infections Prevention Network |
| Dr Peter Mills | President (elect) | Scottish Society of Gastroenterology |
| Dr Mary Ramsay | Consultant Epidemiologist | Centre for Infections, Health Protection Agency |
| Ms Hazel Robertson | Principal Planning Officer | Association of Directors of Social Work |
| Dr Nicola Rowan | Director | UK Hepatitis C Resource Centre |
| Ms Cathy Scott | Chair | Viral Hepatitis Nurses Group |
| Ms Jane Spence | Project Portfolio Manager | National Services Scotland Corporate Programme Office |
| Dr Elizabeth Stewart | Senior Medical Officer | Scottish Government |
| Professor Howard Thomas | Chair | UK Department of Health's Advisory Group on Hepatitis |
| Dr Andrew Walker | Senior Lecturer | Economic Advice |
| Dr Richard Watson | Clinical Lead for Drug Misuse Training Programme | Royal College of General Practitioners |
| Mr Simon White [1] | Project Manager | National Services Scotland, Corporate Programme Office |
| Mr Tom Wood | Chair | Scottish Association of Alcohol and Drug Action Teams |

[1] Formerly Mr Duncan Wilkie

# Appendix 2: Testing, Treatment, Care and Support Working Group Membership

| Name | Position | Organisation |
|---|---|---|
| Dr John Dillon | Chair – Testing, Treatment, Care and Support Working Group | NHS Tayside |
| Ms Amanda Burridge | Personal Assistant to Dr John Dillon | |
| Professor David Goldberg | Chair – Action Plan Co-ordinating Group | Health Protection Scotland |
| Dr Syed Ahmed | Chair - Executive Leads Working Group | NHS Greater Glasgow and Clyde |
| Mr Gareth Brown | Policy Manager | Scottish Government Public Health and Wellbeing Directorate |
| Dr Sheila Cameron | Principal Scientist | West of Scotland Specialist Virology Centre |
| Mr David Cameron | Manager, C Plus | UK Hepatitis C Resource Centre |
| Ms Jacqueline Campbell | Public Health Team Lead | Scottish Government Public Health and Wellbeing Directorate |
| Dr Andrew Fraser | Consultant Hepatologist | NHS Grampian |
| Dr Richard Grieve | Health Economist | London School of Hygiene and Tropical Medicine |
| Dr Gill Hawkins | Specialist Registrar in Public Health | NHS Greater Glasgow and Clyde |
| Dr Sharon Hutchinson | Analytical Epidemiologist | Health Protection Scotland |
| Dr Nick Kennedy | Consultant in Infectious Diseases | NHS Lanarkshire |
| Ms Miriam King | Project Manager | Health Protection Scotland |
| Ms Alice-Ann Murphy [1] | BBV Specialist Nurse | Scottish Prison Service - HMP Shotts |
| Dr Kennedy Roberts | General Practitioner and Addictions Specialist | Glasgow Addiction Service |
| Mr Ian Robertson | Social Work | Fife Council |
| Dr Kirsty Roy | Epidemiologist | Health Protection Scotland |
| Mr Justin Schofield | Managed Care Network Manager | NHS Greater Glasgow and Clyde |
| Ms Cathy Scott | Clinical Nurse Practitioner | NHS Lothian |
| Ms Jane Spence | Project Portfolio Manager | National Services Scotland Corporate Programme Office |
| Mr Simon White | Project Manager | National Services Scotland Corporate Programme Office |

[1] Formerly Mrs Karen Norrie

# Appendix 3: Prevention Working Group membership

| Name | Position | Organisation |
|---|---|---|
| Professor Avril Taylor | Chair – Prevention Working Group | University of Paisley |
| Ms Catherine McClung | Personal Assistant to Professor Avril Taylor | |
| Professor David Goldberg | Chair – Action Plan Co-ordinating Group | Health Protection Scotland |
| Dr Syed Ahmed | Chair – Hepatitis C Executive Leads | NHS Greater Glasgow and Clyde |
| Mr George Howie | Chair - Education, Training and Awareness-raising Working Group | NHS Health Scotland |
| Mr Robin Bate | Public Health Team | Scottish Government Public Health and Wellbeing Directorate |
| Ms Elaine Bell | Policy Officer | Scottish Government Public Health and Wellbeing Directorate |
| Mr Gareth Brown | Policy Manager | Scottish Government Public Health and Wellbeing Directorate |
| Ms Louise Carroll | Research and Development Officer for Blood Borne Viruses | NHS Greater Glasgow and Clyde |
| Mr James Egan | Head of Policy and Practice | Scottish Drugs Forum |
| Dr Michelle Gillies | Clinical Lecturer/Specialist Registrar in Public Health | University of Glasgow/NHS Greater Glasgow and Clyde |
| Dr Matthew Hickman | Senior Lecturer | Bristol University |
| Ms Miriam King | Project Manager | Health Protection Scotland |
| Dr Donna MacKinnon | Principal Research Officer, Drugs Research Team | Scottish Government Justice Department |
| Ms Ruth Parker | Acting Additions Co-ordinator | Scottish Prison Service |
| Miss Norah Palmateer | Epidemiologist | Health Protection Scotland |
| Dr Roy Robertson | Honorary Clinical Reader and General Practitioner | Muirhouse General Practice, Edinburgh |
| Dr Nicola Rowan | Director | UK Hepatitis C Resource Centre |
| Ms Jane Spence | Project Portfolio Manager | National Services Scotland Corporate Programme Office |
| Mr Liam Wells | Team Manager for Youth and Addiction Services | East Ayrshire Council |
| Mr Simon White | Project Manager | National Services Scotland Corporate Programme Office |
| Mr Leon Wylie | National Substance Use Support Officer (Drugs) | Scottish Association of Alcohol and Drug Action Teams |

# Appendix 4: Education, Training and Awareness-raising Working Group Membership

| Name | Position | Organisation |
|---|---|---|
| Mr George Howie | Chair – Education, Training and Awareness-raising Working Group | NHS Health Scotland |
| Mrs Josephine Haigh | Health Improvement Programme Officer | NHS Health Scotland |
| Professor David Goldberg | Chair – Action Plan Co-ordinating Group | Health Protection Scotland |
| Mr Robin Bate | Public Health Team | Scottish Government Public Health and Wellbeing Directorate |
| Ms Helena Bayler | Patient Representative | Patient Representative |
| Mr Gareth Brown | Policy Manager | Scottish Government Public Health and Wellbeing Directorate |
| Dr Margaret Brown | Project Leader | NHS Education Scotland |
| Mr John Brunton | Patients in Quality Division | Scottish Government Public Health and Wellbeing Directorate |
| Dr John Budd | General Practitioner | NHS Lothian |
| Ms Jacqueline Campbell | Public Health Team Lead | Scottish Government Public Health and Wellbeing Directorate |
| Mr Brian Coane | Account Director | Leith Agency |
| Mr Philip Dolan | Chairman | Scottish Haemophilia Forum |
| Mr James Egan | Head of Policy and Practice | Scottish Drugs Forum |
| Mr Charles Ferrier | Senior Marketing Manager | Scottish Government |
| Mr Stephen Heller-Murphy | Addictions Policy and Development Manager | Scottish Prison Service |
| Mr Allan Johnston | Business Development and Operations Manager | Scottish Training on Drugs and Alcohol |
| Ms Miriam King | Project Manager | Health Protection Scotland |
| Ms Trish Quinn | Senior Marketing Manager | Scottish Executive |
| Dr Nicola Rowan | Director | UK Hepatitis C Resource Centre |
| Dr Kirsty Roy | Epidemiologist | Health Protection Scotland |
| Ms Jane Spence | Project Portfolio Manager | National Services Scotland Corporate Programme Office |
| Mrs Jan Tait | Clinical Nurse Specialist in Gastroenterology | NHS Tayside |
| Ms Lynda Tweddle | BBV Health Improvement Training Officer | NHS Dumfries and Galloway |
| Mr Simon White | Project Manager | National Services Scotland Corporate Programme Office |
| Mr Leon Wylie | National Substance Use Support Officer (Drugs) | Scottish Association of Alcohol and Drug Action Teams |

# Appendix 5: Implementation Group membership

| Name | Position | Organisation |
|---|---|---|
| Professor David Goldberg[1] | Chair – Action Plan Co-ordinating Group | Health Protection Scotland |
| Dr Syed Ahmed | Chair – Hepatitis C Executive Leads | NHS Greater Glasgow and Clyde |
| Mr Gareth Brown | Policy Manager | Scottish Government Public Health and Wellbeing Directorate |
| Ms Jacqueline Campbell | Public Health Team Lead | Scottish Government Public Health and Wellbeing Directorate |
| Mrs Ellen Carragher[1] | Administrator | Health Protection Scotland |
| Dr John Dillon | Chair – Testing, Treatment, Care and Support Working Group | NHS Tayside |
| Mr George Howie | Chair – Education, Training and Awareness-raising Working Group | NHS Health Scotland |
| Dr Sharon Hutchinson[1] | Analytical Epidemiologist | Health Protection Scotland |
| Ms Miriam King[1] | Project Manager | Health Protection Scotland |
| Miss Norah Palmateer | Epidemiologist | Health Protection Scotland |
| Dr Kirsty Roy | Epidemiologist | Health Protection Scotland |
| Ms Jane Spence[1] | Project Portfolio Manager | National Services Scotland Corporate Programme Office |
| Professor Avril Taylor | Chair – Prevention Working Group | University of Paisley |
| Mr Simon White[1] | Project Manager | National Services Scotland Corporate Programme Office |

[1] Member of Project Team

# Appendix 6: NHS Board Hepatitis C Executive Lead Group membership

| Name | Position | Organisation |
|---|---|---|
| Dr Syed Ahmed | Chair – Hepatitis C Executive Leads Working Group and Consultant in Public Health Medicine | NHS Greater Glasgow and Clyde |
| Ms Heather Telford | Personal Assistant to Dr Syed Ahmed | |
| Professor David Goldberg | Chair – Action Plan Co-ordinating Group and Consultant in Public Health Medicine | Health Protection Scotland |
| Dr Eric Baijal | Director of Public Health | NHS Highland |
| *Dr Duncan McCormick - deputy for Dr Eric Baijal* | | |
| Dr Ken Black | Consultant in Public Health Medicine | NHS Orkney |
| Dr David Breen | Consultant in Public Health Medicine | NHS Dumfries and Galloway |
| Mr George Cunningham | General Manager | Kirkcaldy and Levenmouth CHP |
| Dr Carol Davidson | Director of Public Health | NHS Ayrshire and Arran |
| Ms Miriam King | Project Manager | Health Protection Scotland |
| Dr John Logan | Consultant in Public Health Medicine | NHS Lanarkshire |
| Dr Alison McCallum | Director of Public Health | NHS Lothian |
| *Dr Christine Evans deputy for Dr Alison McCallum* | | |
| Dr Bill Mutch | Board Medical Director | NHS Tayside |
| *Mrs Ann Eriksen - deputy for Bill Mutch* | | |
| Dr Tim Patterson | Consultant in Public Health Medicine | NHS Borders |
| Dr Henry Prempeh | Consultant in Public Health Medicine | NHS Forth Valley |
| Dr Maria Rossi | Consultant in Public Health Medicine | NHS Grampian |
| Dr Maida Smellie | Consultant in Public Health Medicine | NHS Ayrshire and Arran |
| Dr Sarah Taylor | Director of Public Health | NHS Shetland |
| Mr Simon White | Project Manager | National Services Scotland Corporate Programme Office |
| Mrs Julie Yates | Public Health Nurse Consultant | NHS Western Isles |

# Appendix 7: Summary of Phase II Action Plan actions

| Issues | Actions | Outcome | Lead Organisation(s) (Recipient(s) of funding) | Lead Network(s) supporting the delivery of Action | Performance Indicator(s) | Timescale(s) |
|---|---|---|---|---|---|---|
| **Testing, Treatment, Care and Support** | | | | | | |
| Widespread variations in the approach to the clinical management and social care of Hepatitis C infected persons exist across Scotland. Only two NHS Boards have a Managed Care Network (MCN) for Hepatitis C and although guidelines on the clinical management of persons with Hepatitis C exist, formal standards do not. | **1.** Each NHS Board will have, or be affiliated to, an MCN for Hepatitis C; this Network will comprise representatives of relevant specialists in healthcare and other stakeholder groups including those for the prison service, local authority, social work, the voluntary sector, mental health/addictions, and people living with and affected by Hepatitis C. The Network will be guided in its practice through the use of "Care" Guidelines, prepared by the Hepatitis C Action Plan's Testing, Treatment, Care and Support Working Group, and the Scottish Intercollegiate Guidelines Network (SIGN) guidelines on the management of Hepatitis C. | These actions will ensure that approaches to the diagnosis and management of Hepatitis C infected persons throughout Scotland are highly effective and, where appropriate, consistent. | NHS Boards | Hepatitis C Executive Leads Network | MCN accreditation. | First meeting of new MCNs by July 2008, towards full establishment by end of 2008, and accreditation by 2010. |
| | **2.** NHS Quality Improvement Scotland (QIS) will develop standards for Hepatitis C testing and the treatment, care and social support of persons with Hepatitis C infection. | | NHS QIS | MCN Leads Network | Auditing against the published standards. | NHS QIS standards developed by 2010. |
| The training of the Hepatitis C workforce is ad hoc and often sub-standard with no alignment to quality frameworks. | **3.** A national Hepatitis C Learning and Workforce Development Framework will be developed. | These actions will ensure that Scotland's Hepatitis C Workforce in its entirety is knowledgeable, skilled and confident. | NHS Education for Scotland | Education, Training and Awareness-raising Network | MCN accreditation (see action 1). | Framework developed and published by March 2009, and implemented throughout 2009-2011. |
| | **4.** NHS Boards, working with their partners, will identify a Hepatitis C Workforce Development Lead, review the learning and development needs of the Hepatitis C workforce, and implement a co-ordinated approach to Hepatitis C Workforce Development consistent with the national Hepatitis C Learning and Workforce Development Framework. | | NHS Boards | i) Education, Training and Awareness-raising Network;<br>ii) MCNs;<br>iii) Prevention Networks;<br>iv) NGOs Network | MCN accreditation and review against NHS QIS Standards. | Workforce Development Leads identified by September 2008. The learning and development needs of the Hepatitis C workforce reviewed by March 2009. A co-ordinated approach to Hepatitis C workforce development implemented throughout 2009-2011. |

| Issues | Actions | Outcome | Lead Organisation(s) (Recipient(s) of funding) | Lead Network(s) supporting the delivery of Action | Performance Indicator(s) | Timescale(s) |
|---|---|---|---|---|---|---|
| | **5.** Awareness-raising campaigns and communications initiatives will continue to be developed, implemented and evaluated to meet the information and education needs of a range of professional audiences (including those responsible for the delivery of prevention services). | | Scottish Government | i) Education, Training and Awareness-raising Network;<br>ii) MCNs;<br>iii) Prevention Networks;<br>iv) NGOs Network | Awareness and knowledge of Hepatitis C through national surveys. | Campaigns and communications activity implemented and evaluated throughout 2008-2011. |
| Insufficient numbers of Hepatitis C infected persons, including prisoners, receive antiviral therapy. | **6.** Testing, Treatment, Care and Support services within each NHS Board will be developed to increase the numbers of persons undergoing therapy in Scotland from 450/year to 500 in 2008/09, 1,000 in 2009/10, 1,500 in 2010/11 and at least, 2,000/year thereafter. | These actions will increase the numbers of infected persons who clear their infection and thus reduce the numbers of infected persons who develop severe Hepatitis C-related liver disease. | i) NHS Boards;<br>ii) Scottish Government (for National Voluntary Sector contribution), iii) National Services Division of National Services Scotland (Hepatitis C specialist laboratory work) | i) MCNs;<br>ii) MCN Leads Network | Number of persons offered antiviral therapy. Number of persons commenced on antiviral therapy. Proportion of those having received antiviral therapy who achieve a sustained viral response. | Targets for 2008-2011 as indicated. |
| | **7.** Service Level Agreements / Memoranda of Understanding, between NHS Boards and the Scottish Prison Service (SPS), to promote the treatment of Hepatitis C infected inmates in prisons, will be developed in the context of the SPS Blood Borne Virus (BBV) strategy. | | SPS | i) MCNs;<br>ii) MCN Leads Network | Number of persons offered antiviral therapy (prisons only). Number of persons commenced on antiviral therapy (prisons only). Proportion of those having received antiviral therapy who achieve a sustained viral response (prisons only). | SLAs/MoUs developed by November 2008. Targets for 2008-2011 as indicated above (see Action 6). |

| Issues | Actions | Outcome | Lead Organisation(s) (Recipient(s) of funding) | Lead Network(s) supporting the delivery of Action | Performance Indicator(s) | Timescale(s) |
|---|---|---|---|---|---|---|
| In many parts of Scotland there are insufficient links between social care/addiction/mental health services and specialist services for Hepatitis C treatment. It is not possible to manage and treat Hepatitis C infected persons without considering their social care and drug/alcohol problem needs. There is a paucity of local authority (social care) involvement with Hepatitis C infected persons across Scotland. | **8.** For each NHS Board a formal plan, indicating how it has integrated or will integrate appropriate elements of Hepatitis C specialist treatment services into those for social care, mental health and addiction in local authority, voluntary sector, primary care and secondary care settings, will be developed and implemented. | An integrated approach to the management of Hepatitis C infected persons involving Hepatitis C treatment, social care, and mental health/addiction will be fostered. | NHS Boards | i) MCNs;<br>ii) NGOs Network | MCN accreditation. | Plan developed by March 2009 and implemented throughout 2009-2011. |
| | **9.** Each local authority will identify a Strategic and Operational Lead for Hepatitis C infection. | | Local Authorities | MCNs | Local Authority lead identified. | Leads identified by July 2008. |
| The majority of persons chronically infected with Hepatitis C remain undiagnosed and many of those diagnosed fail to reach and stay within specialist care services. There are widespread variations in testing practice in the community setting. The uptake of Hepatitis C testing among past/current injecting drug users (IDUs) is sub-optimal following test offer. | **10.** NHS Boards will work with Community Health Partnerships (CHPs) to develop and implement a plan, incorporating innovative approaches, to improve Hepatitis C testing and referral activities by General Practitioners (GPs) and other community setting practitioners. | These actions will reduce the proportion of Hepatitis C infected individuals who are undiagnosed. | NHS Boards | MCNs | Numbers of persons Hepatitis C tested, diagnosed and referred to specialist care services by GPs and other community setting practitioners. | Plan developed by March 2009 and implemented throughout 2009-2011. |
| | **11.** An awareness-raising campaign, to promote Hepatitis C testing among those at risk of being infected, will be implemented and evaluated. | | Scottish Government | i) Education, Training and Awareness-raising Network;<br>ii) NGOs Network | Awareness and knowledge of Hepatitis C through national surveys. Numbers of persons Hepatitis C tested and diagnosed. | Campaign implemented by September 2009, and evaluated by September 2010. |
| | **12.** A programme of work to evaluate different approaches to Hepatitis C testing/body fluid sampling (e.g. near patient testing/use of saliva and dried blood spots) will be undertaken. | | BBV Specialist Laboratories (via Health Protection Scotland) | MCN Leads Network | Measures of acceptability and effectiveness of different approaches. | Programme designed in 2008-2009, evaluated throughout 2009-2010, and reported in 2010. |

| Issues | Actions | Outcome | Lead Organisation(s) (Recipient(s) of funding) | Lead Network(s) supporting the delivery of Action | Performance Indicator(s) | Timescale(s) |
|---|---|---|---|---|---|---|
| **Prevention** | | | | | | |
| Widespread variations in the provision and uptake of injection equipment and educational initiatives to prevent Hepatitis C transmission exist throughout Scotland. NHS Boards do not have formal networks to facilitate the prevention of Hepatitis C. Other than guidelines on the number of sets of needles/syringes that can be given to IDUs, comprehensive National Guidelines for services providing injection equipment do not exist. | **13.** Each NHS Board will have, or be affiliated to, a Network covering the Prevention of Hepatitis C and comprising representatives of all stakeholder sectors. Guidance regarding Network membership and Terms of Reference for the Hepatitis C component will be established. Each NHS Board will identify a Hepatitis C Prevention Lead. | These actions will ensure that approaches to the provision of injection equipment to IDUs throughout Scotland are highly effective and, where appropriate, consistent. | NHS Boards | i) Hepatitis C Executive Leads Network;<br>ii) Prevention Leads Network;<br>iii) Guidelines Development Group | Audit against the guidelines (see action 14). | Prevention Leads identified by July 2008. Hepatitis C requirements for the Network agreed and implemented by September 2008. |
| | **14.** National guidelines for services providing injection equipment to IDUs will be developed. A Guideline Development Group will be established. | | Scottish Government | Guideline Development Group | Audit against the guidelines. | Guideline Development Group established by May 2008. Interim guidelines published by December 2008. Final guidelines published by July 2009. |
| The re-use/sharing of injection equipment among IDUs is still highly prevalent and Hepatitis C transmission among IDUs throughout Scotland is very common. | **15.** Services providing injection equipment (needles/syringes and other injection paraphernalia) will be improved in accordance with guidelines (see action 14). Improvements will be made in terms of the, i) quantity (increasing access and uptake of equipment through innovative, including outreach, approaches), ii) quality (e.g. the colour coding of equipment to avoid sharing) and iii) nature (e.g. provision of equipment other than needles/syringes), of provision. | These actions, hopefully, will lead to reductions in injection equipment sharing and Hepatitis C transmission among IDUs. | NHS Boards | i) Prevention Networks;<br>ii) Prevention Leads Network | Proportion of injection episodes undertaken with sterile injecting equipment (needles/syringes and other injecting paraphernalia). Proportion of IDUs sharing injecting equipment. Hepatitis C prevalence/incidence among recent onset injectors. Baseline data will be available in 2008 and, thereafter, targets will be set. | Plan of action for each Network developed by March 2009, and implemented throughout 2009-2011. |
| | **16.** Educational interventions aimed at vulnerable individuals, IDUs and those at risk of starting to inject will be designed and implemented to highlight how Hepatitis C transmission can be prevented. Particular attention should be given to initiatives aimed at identifying existing and newly diagnosed IDUs with Hepatitis C to prevent the onward transmission of infection. | | i) NHS Health Scotland;<br>ii) NHS Boards | i) Prevention Networks;<br>ii) Prevention Leads Network;<br>iii) Education, Training and Awareness-raising Network;<br>iv) NGOs Network | See action 15. | Interventions designed by March 2009, and implemented throughout 2009-2011. |

| Issues | Actions | Outcome | Lead Organisation(s) (Recipient(s) of funding) | Lead Network(s) supporting the delivery of Action | Performance Indicator(s) | Timescale(s) |
|---|---|---|---|---|---|---|
| IDUs who continue to inject drugs in prison do not have access to injection equipment in that setting. | **17.** An in-prison needle/syringe exchange initiative will be piloted as one of a range of harm reduction measures to reduce the transmission of Hepatitis C. | This action will demonstrate the acceptability, to users and prison officers, and use of an in-prison service providing injection equipment. | SPS | i) Prevention Leads Network;<br>ii) Relevant NHS Board Prevention Network(s) | Measures of use and acceptability. | Initiative implemented and externally evaluated by 2011 |
| Persons in school and further education settings receive little, if any, education about Hepatitis C. | **18.** Hepatitis C guidance and educational support materials (within the context of BBVs/drug misuse) will be developed, disseminated and evaluated to raise awareness among young people in school, and further education and community settings, and other settings which support vulnerable young people. Staff/peer group training initiatives will facilitate the implementation of this action. | This action will increase awareness and knowledge of Hepatitis C among young people in Scotland. | Learning and Teaching Scotland | i) Education, Training and Awareness-raising Network;<br>ii) NGOs Network | Levels of Hepatitis C education (within the context of BBVs/drug misuse) in schools and further education, and community settings, and other settings supporting vulnerable young people. Knowledge of Hepatitis C among young people and young adults (within the context of BBVs/drugs misuse). | Materials developed by June 2009, disseminated by September 2009, and evaluated by March 2011. |
| **Information Generating Initiatives to Monitor the Performances of Actions** | | | | | | |
| Clinical data to monitor the performance of actions 6 and 7 are required. | **19.** The further development of the National Hepatitis C Clinical Database, including the establishment of a Generic Clinical System for Hepatitis C will be undertaken. | This action will ensure that measures to improve treatment, care and support services for Hepatitis C infected individuals, and thus reduce their chances of progressing to severe Hepatitis C-related disease, are evaluated effectively. | Health Protection Scotland | i) Action Plan Information Generating Initiatives Network<br>ii) Hepatitis C Clinical Database Monitoring Group; | (see Outcome) | Generic Clinical System for Hepatitis C established by December 2009. Progress and available NHS Board data published in Annual Report by May 2009, and all NHS Board data published in Annual Report by May 2010. |

| Issues | Actions | Outcome | Lead Organisation(s) (Recipient(s) of funding) | Lead Network(s) supporting the delivery of Action | Performance Indicator(s) | Timescale(s) |
|---|---|---|---|---|---|---|
| Data to monitor the performance of actions 10 and 11 are required. | **20.** The development of a surveillance system to monitor Hepatitis C testing practice in Scotland will be undertaken. | This action will ensure that awareness campaigns aimed at reducing the proportion of infected persons who are undiagnosed are evaluated effectively. | Health Protection Scotland | Action Plan Information Generating Initiative Network | (see Outcome) | Hepatitis C Test Database relating to all NHS Boards established by December 2009. Progress and available NHS Board data published in Annual Report by May 2009, and all NHS Board data published in Annual Report by May 2010. |
| Data to monitor the performance of actions 14-16 are required. | **21.** The development of a data collection system to monitor the provision of injection equipment in Scotland will be undertaken. | These actions will ensure that the package of interventions designed to increase uptake and reduce sharing of injection equipment, and reduce Hepatitis C transmission, among IDUs is evaluated effectively. | Information Services Division | Action Plan Information Generating Initiative Network | (see Outcome) | Data collection system on Injecting Equipment Provision established by June 2009. Data published annually in relevant reports, such as Drug Misuse Statistics Scotland by December 2009. |
| | **22.** Annual surveys of Hepatitis C prevalence and incidence among IDUs across Scotland will be performed. | | i) Health Protection Scotland;<br>ii) University of the West of Scotland | Action Plan Information Generating Initiative Network | (see Outcome) | Surveys undertaken annually and data published in Annual Report by May 2009. |

| Issues | Actions | Outcome | Lead Organisation(s) (Recipient(s) of funding) | Lead Network(s) supporting the delivery of Action | Performance Indicator(s) | Timescale(s) |
|---|---|---|---|---|---|---|
| If the performance of actions involving the development of prevention, diagnosis, treatment, care and support services in the prison setting is to be gauged, it is important that the proportion of Scotland's prison population who are Hepatitis C infected, the proportion of this group who are undiagnosed and the incidence of Hepatitis C transmission among prison inmates, is understood.<br><br>Also, if a sound understanding of the Hepatitis C diagnosis, treatment, care and support needs of i) children and, ii) persons originating from Pakistan (and, possibly, other South Asian countries) – populations about whom little is known, apropos the proportions infected with Hepatitis C – is to be achieved, it is essential that prevalence studies on these groups are undertaken. | **23.** A survey of Hepatitis C prevalence and incidence among prisoners in Scotland will be undertaken.<br><br>**24.** Surveys to estimate the prevalence of Hepatitis C among i) children in Scotland and, ii) people in Scotland who have lived in Pakistan (and, possibly, other South Asian countries) will be undertaken. | These actions will generate data to inform the needs of Hepatitis C infected prisoners, children and Pakistanis and will ascertain how effective measures to prevent the spread of Hepatitis C within the prison selling have been. | SPS<br><br>Health Protection Scotland | Action Plan Information Generating Initiative Network | (see Outcome) | Surveys undertaken and data published in reports by March 2011. |
| **Co-ordination** | | | | | | |
| To ensure that the Action Plan is delivered efficiently, effectively, to timescales, and is governed appropriately, a range of actions at national and local levels will be implemented (see text for detailed understanding of Action Plan co-ordination). | | | | | | |

| Issues | Actions | Outcome | Lead Organisation(s) (Recipient(s) of funding) | Lead Network(s) supporting the delivery of Action | Performance Indicator(s) | Timescale(s) |
|---|---|---|---|---|---|---|
| **National** | **25**. An Action Plan Advisory Board to advise and comment on issues concerning Action Plan progress and performance will be established. | These actions will ensure the successful delivery of the Action Plan. | Scottish Government | | Measures of progress on, and performance of, actions 1-24 (see above). | Action Plan Advisory Board established by July 2008. |
| | **26**. National Networks to support NHS Boards and other organisations delivering the Action Plan will be established and maintained. | These actions will ensure the successful delivery of the Action Plan. | Health Protection Scotland | | | National Networks established by July 2008. |
| | **27.** Action Plan progress and performance will be monitored; an Action Plan Governance Board will be established to facilitate this action. | | Health Protection Scotland | | | Action Plan Governance Board established by July 2008. |
| | **28**. Communications activities (e.g. Annual reports, website development and annual Stakeholder Conference) to keep stakeholders abreast of, and receive feedback on, Action Plan progress, will be undertaken. | | Health Protection Scotland | | | Preliminary website developed by May 2008, with full development by December 2008. Annual Report by May 2009. UK Annual Report by November 2008. Annual Stakeholder Conference in May 2009. |
| | **29**. To undertake the above actions, a Project Management approach will be employed. | | Health Protection Scotland | | | Project Management approach employed by July 2008, and embedded thereafter. |

| Issues | Actions | Outcome | Lead Organisation(s) (Recipient(s) of funding) | Lead Network(s) supporting the delivery of Action | Performance Indicator(s) | Timescale(s) |
|---|---|---|---|---|---|---|
| **Local** | **30**. Local/Regional Networks to support the delivery of services will be established and maintained. | These actions will ensure the successful delivery of the Action Plan. | NHS Boards | | Measures of progress on, and performance of, actions 1-24 (see above). | Networks fully established by December 2008. |
| | **31**. Local progress and performance will be monitored and support will be given to HPS and the Action Plan Governance Board to facilitate their national monitoring roles. | | NHS Boards | | | Progress and performance mechanism agreed by September 2008 with reporting thereafter. |
| | **32**. Communications activities to keep stakeholders abreast of, and receive feedback on, Action Plan progress will be undertaken; support will be provided for national communications initiatives. | | NHS Boards | | | Communications plan developed by September 2008. |
| | **33**. Services will be commissioned. | | NHS Boards | | | Services commissioned throughout 2008-2011. |
| | **34**. To undertake the above actions, a Project Management approach will be employed. | | NHS Boards | | | Project Management approach employed by July 2008 and embedded thereafter. |