

HEPATITIS C PROPOSED ACTION PLAN IN SCOTLAND

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Introduction

- 1.1 The growing importance of hepatitis C as a public health issue in this country was highlighted in 2000 with the publication of a report by the Scottish Needs Assessment Programme (SNAP). The SNAP report brought together existing initiatives to tackle hepatitis C and made recommendations on how prevention, diagnosis and treatment could be improved.
- 1.2 This Action Plan is designed to promote further implementation of the SNAP recommendations and the key messages in the Consensus Statement which emerged from the Conference in the Royal College of Physicians of Edinburgh in April 2004. It also draws on the evidence from the findings of research studies published by the Effective Interventions Unit in the Scottish Executive Health Department.
- 1.3 The Action Plan is intended to cover the period 2005 to 2007.

Objectives

- 1.4 There are three principal objectives:
 - 1) To reduce the transmission of Hepatitis C virus (HCV) among current injecting drug users (IDUs).
 - 2) To diagnose infected persons, particularly those who are most in need of therapy.
 - 3) To provide the optimal care and support for HCV diagnosed persons who are able to benefit.

Funding Issues

- 1.5 This Action Plan is based on current funding. The implementation of the Actions will highlight the areas where funding needs to be reviewed.
- 1.6 The Scottish Executive currently provides funding to NHS Boards of over £8m, in earmarked resources, to assist in their efforts to prevent the spread of bloodborne viruses, including HIV and hepatitis C. How the funding is distributed between NHS Boards is currently under review. The current formula for funding is based on HIV prevalence. The new formula will not only take account of the number of those with HIV but also those with hepatitis C.
- 1.7 In addition to the specific allocation for Blood Borne Viruses, Health Boards are given a unified budget to meet the health care needs of their resident population. It is for Boards to decide how best to utilise this funding to meet local and national priorities including the treatment and prevention of Hepatitis C.

How will we ensure the Plan is implemented?

- 1.8 Health Protection Scotland (HPS) will co-ordinate a HCV Prevention and Care Strategy by ensuring that Scotland's Hepatitis C Action Plan is implemented effectively by lead agencies.

Summary of Actions for Lead Organisations

Timescale for implementation – 2005 to 2007

HPS

- Establish and lead a Hepatitis C Action Plan Co-ordinating Group (ACPG) accountable to the Scottish Health Protection Advisory Group and to the Chief Medical Officer to develop, implement and evaluate the plan's actions.
- Appoint a clinical scientist to support the ACPG administratively and scientifically.
- Produce a Hepatitis C Action Plan Annual Report which will provide the latest information on the epidemiology of HCV in Scotland and indicate progress being made on the Action Plan.
- Establish an inventory of HCV prevention activity measures so that the implementation and effectiveness of policies aimed at reducing infection among target populations can be monitored and evaluated.
- Further develop surveillance initiatives to monitor the prevalence and incidence of HCV and related behaviours (including HCV test uptake) among injecting drug users.
- Further develop modelling to estimate the future burden of HCV disease in Scotland including cost implications for the NHS in Scotland.
- Support clinicians in establishing and maintaining a database of the treatment and care characteristics of all persons entering HCV specialist services.

Health Scotland

- Produce relevant information materials for professionals, employers, those at risk of contracting HCV and those who are already infected to give information about reducing harm and the risk of other hepatitis infections.
- Develop and make available a national system - similar to that currently in use in NHS Greater Glasgow - whereby a diagnosis of HCV triggers information to both the individual and the GP, and ensure it is available nationally.
- Develop a two fold approach to awareness raising which will provide information to public, and a more targeted approach through the primary care route.
- Co-ordinate with stakeholders on a low key information campaign through the press to improve public awareness of HCV. Information about blood-borne viruses in general should also be included where appropriate in school-based health education.

Scottish Executive Health Department (SEHD)

- Contribute to the update of current clinical guidelines on Drugs Misuse and Dependence – Guidelines on Clinical Management.
- With partners take forward the recommendations set out in the strategy for pharmacist's document "Prevention and Treatment of Substance Misuse".
- Undertake a national needle exchange survey together with colleagues in England, Wales and Northern Ireland. Report will be available in Autumn 2005.
- Support the development of MCNs in Scotland to ensure equity of access to all people with HCV and that models of best practice are followed and subject to audit.
- Work with Health Scotland and HPS to roll out a low key information campaign through the press to improve public awareness of HCV.
- Work with NHS Boards to make better use of the new GMS contract.

NHS Education for Scotland (NES)

- Undertake a mapping exercise to determine what provisions for education and training are currently available to statutory, non-statutory and voluntary organisations so that any gaps in provision are identified.
- Working on multi-agency and multi-disciplinary basis to develop education and awareness raising tools for health care workers, social care workers and staff in voluntary support agencies. Undertake increasing awareness and understanding amongst a broad range of professional groups.

Royal College of General Practitioners (RCGP)

- Will deliver improved training and education for GPs, specialists and other health professionals involved in prescribing through the extension of the provision of RCGP Certificates in the Management of Drugs Misuse, from 2005/06.
- Implementation of guidance to GPs on the vaccination of close family contacts of drug injectors against Hepatitis A and B.

NHS Boards

- Once the revised clinical guidelines “Drug Misuse and Dependence – Guidelines on Clinical Management” are available Clinical Governance leads supported by Prescribing Advisors will ensure that prescribing practice is brought in line with current evidence and the new guidelines.
- Designate, at Director level, a Bloodborne Virus Co-ordinator who will be responsible for reporting to HPS on the progress being made in implementing and evaluating the Action Plan in their Board area.
- Develop and implement interventions to reduce needle sharing, syringes and injecting paraphernalia and promote safer injection practice. Measures should include more outreach and injecting equipment exchanges.
- Use the full available potential of the new General Medical Services (GMS) contract.

Scottish Prison Service (SPS)

- Develop and implement interventions to reduce needle sharing, syringes and injecting paraphernalia and promote safer injection practice.
- Will work to improve education and awareness raising among current IDU’s about HCV.
- Develop an intervention to discourage current injectors from initiating others into injecting – based on the Break the Cycle intervention.

Scottish Viral Hepatitis Group

- Develop Managed Clinical Networks (MCNs) in Scotland to ensure equity of access to all people with HCV and to ensure that models of best practice are followed and subject to audit.
- Establish and maintain a database of the treatment and care characteristics of all persons entering HCV specialist services.

Community Health Partnerships

- Increase the availability of up to date information to the patient and their carers, public and professionals.

SIGN Group

- Develop guidelines for the diagnosis, treatment and care of people with HCV.

Section 1: Prevention

Issue

The main known route of transmission for HCV in Scotland is through injecting drug use because of risk behaviours such as sharing and re-using of syringes and other injecting equipment. Prevention efforts need to be intensified to reduce the spread of HCV in at-risk populations.

Actions

1. Reducing transmission among current injecting drug users

- a) SEHD and the UK Health Departments are currently revising at present the clinical guidelines on “Drug Misuse and Dependence – Guidelines on Clinical Management”. Thereafter, Clinical Governance leads in NHS Boards supported by Prescribing Advisors should ensure that **prescribing practice should be brought in line with current evidence and the new guidelines.**
- b) The Royal College of General Practitioners (RCGP) will deliver **improved training and education for GPs, specialists and other health professionals** involved in prescribing through the extension of the provision of RCGP Certificates in the Management of Drugs Misuse being extended to Scotland, from 2005/06.
- c) The RCGP will implement their **guidance for GPs on the vaccination of close family contacts** etc of drug injectors against Hepatitis A and B.
- d) SEHD with partners/Pharmaceutical Committee will take forward the recommendations set out in the strategy for pharmacist’s document “Prevention and Treatment of Substance Misuse”. Will shortly be available at www.show.scot.nhs.uk .
- e) The SPS and other organisations that have contact with IDUs will work to **improve education and awareness raising** among this population.
- f) NHS Boards and SPS will **develop and implement interventions to reduce re-using and sharing of needles, syringes and injecting paraphernalia and to promote safer injection.** These interventions could include: more outreach and mobile injecting equipment exchanges; distributing a wider range of paraphernalia, not only needles and syringes at needle exchanges; and labelling or colour coding of equipment to help drug users identify their own.
- g) SEHD will undertake a national needle exchange survey together with colleagues in England, Wales and Northern Ireland. The survey will map needle exchange facilities across the UK, describe current service provision, identify the gaps in service provision, and explore what is and is not working well in this area. A report of the survey will be available by Autumn 2005.

2. Preventing initiation into injecting

- a) **Reduce initiation into injecting** – NHS Boards and SPS will develop an intervention to give current injectors the skills to resist requests to initiate other drug users into injecting (based on the Break the Cycle intervention.) Further details are available at <http://www.exchangesupplies.org/campaignmaterials/btcbrief.html>
- b) Education and awareness raising among potential injectors, particularly in the SPS.

3. Raising awareness among Staff and Organisations working with Drug Users

- a) **Education and Training** – Health Scotland and NES working with Scottish Training on Drugs and Alcohol (STRADA) will develop (on a multi-agency and multi-disciplinary basis) education and awareness materials about the risks of injecting drug use. Specific actions should include: the wide dissemination and use of a video about injecting practices produced for drug workers which is based on research into injecting practices published in 2004; and the development of professional briefing materials with particular focus on staff who do not have regular contact with the client group.
- b) Health Scotland and NES with stakeholders will work to raise awareness and understanding of HCV amongst a broad range of professional groups from the statutory, independent and voluntary sectors.

Section 2: High Quality Health and Social Care Services

Issue

Current management of known hepatitis C patients is not standardized across Scotland. The patient pathway between primary and secondary care also needs to be more integrated.

Actions

1) Development of Managed Clinical Networks - SEHD and the Scottish Viral Hepatitis Group will support the development of MCNs in Scotland. This will help to ensure that there is equity of access to treatment and care for all people with HCV and that models of best practice are followed and audited. For a full description of the role and responsibility of a MCN, please see NHS Circular: HDL (2002) 69 available at www.show.scot.nhs.uk .

2) Development of a SIGN Guideline – The SIGN group will develop guidelines for the diagnosis, treatment and care of people with HCV.

3) Community Health Partnerships will have the devolved responsibility to make available to the public information about local statutory and non-statutory services. This will be useful in increasing the availability of up-to-date information to the patient and their carers, public and the professionals.

4) NHS Boards will make better use of Primary Care contracting arrangements including enhanced services in the new GMS Contract; section 17C and 2C contracts; new pharmacy and dental contracts. The full potential of the available contractual options is yet to be used by NHS Boards, especially in areas such as the management of people with substance misuse, eg medication, discouraging sharing of injecting equipment or starting the process of injecting.

Section 3: Increasing awareness about hepatitis C

Issue

Many of those who have the HCV are unaware of their status. Increasing awareness aims to minimise transmission through greater knowledge of the routes of transmission and by reaching those who may be unaware they have HCV, to encourage them to come forward for testing. In addition, there is a lack of knowledge and understanding about the subject of HCV – not only among those who have, or are at risk of acquiring the virus, but also among health and social care professionals who could have a crucial role in prevention and treatment.

Actions

1. For those who know they have hepatitis C

Health Scotland working with HPS, SPS and relevant voluntary organisations will ensure there are information materials produced to give information about reducing harm – such as not drinking alcohol; reducing risk of other hepatitis infections through immunization and about preventing transmission to others. This should also include advice and practical help on social and economic issues.

2. For those newly diagnosed

Health Scotland working with HPS, SPS and NHS Boards will work to develop and make available nationally the system which exists in NHS Greater Glasgow whereby a diagnosis of hepatitis C triggers information to both the individual and the GP.

3. For those with hepatitis C, but who are unaware of their infection

Health Scotland with HPS, SPS, primary care, voluntary sector and target groups involvement will develop a two-fold approach. First, general provision of information to the public, and second the development of targeted work through the primary care setting; identifying HCV infected former IDUs is a priority as a large proportion of such individuals now need, and would be eligible for, antiviral therapy.

4. For the General Public

SEHD, Health Scotland and HPS will work together to roll out a low key information campaign through the press to improve public awareness of hepatitis C. Information about blood-borne viruses in general will also be included where appropriate in school-based health education.

5. For professionals

NES working with stakeholders will undertake to increase awareness and understanding amongst a broad range of professional groups from the statutory, independent and voluntary sectors. (Please also see Action 3 under Prevention.)

Section 4: Co-ordination, Monitoring and Research

Issue

Numerous agencies and professional groups in Scotland have been involved in preventing the transmission of, and managing the care of persons with, hepatitis C infection. Further, a plethora of guidelines which relate to hepatitis C prevention and clinical care either exist or are in preparation. In view of the scale and complexity of Scotland's problem, it is essential that a national co-ordinated approach to the development, implementation and evaluation of the Action Plan is introduced.

Action

Between 1995 and 2004, the Scottish Centre for Infection and Environmental Health (SCIEH), in association with stakeholders, established surveillance systems to monitor the spread and clinical burden of HCV infection throughout Scotland. From April 2005, Health Protection Scotland (a new organisation which incorporates SCIEH) will continue its monitoring function, as above, but will also take on the role of co-ordinating the development, implementation and evaluation of the Hepatitis C Action Plan to ensure that knowledge relating to HCV is more effectively translated into health protection action.

Specific Actions

1. Co-ordination

- a) HPS will establish and lead a Hepatitis C Action Plan Co-ordinating Group (Hepatitis C APCG); this will comprise of individuals who will represent all disciplines and Health Board areas which have a stake in the Action Plan. The remit of the group will be to develop, implement and evaluate the plan's actions. The group will be accountable to the Scottish Health Protection Advisory Group and to Scotland's Chief Medical Officer. The Hepatitis C APCG will be supported administratively and scientifically by HPS; this role will be undertaken by a clinical scientist to be appointed by HPS.
- b) NHS Boards (including special Boards) will designate, at Director level, a Bloodborne Virus co-ordinator who will be responsible for reporting to HPS the progress being made in implementing and evaluating the Action Plan in their NHS Board area.
- c) HPS will produce a Hepatitis C Action Plan Annual Report which will provide the latest information on the epidemiology of HCV in Scotland and will indicate progress being made with the plan.

2. Monitoring

- a) Since knowledge about aspects of HCV in Scotland is crucial in informing i) the need for new actions, ii) how well actions are being implemented and iii) how well the actions are performing, the following monitoring initiatives are proposed: *(Other than the treatment and care database which is managed by clinicians (Lead: Professor P Hayes), these initiatives will be co-ordinated by HPS in association with health protection, clinical and virological specialists.)*

b) the establishment of an inventory of HCV prevention activity measures so that the implementation and effectiveness of policies aimed at reducing infection among target populations can be monitored and evaluated.

c) the further development of surveillance initiatives to monitor the prevalence and incidence of HCV and related behaviours (including HCV test uptake) among injecting drug users.

d) the further development of models to estimate the future HCV disease burden in Scotland; particular emphasis will be placed on undertaking economic analyses aimed at measuring i) the cost of screening people for, and treating and managing people with, HCV infection and ii) how these costs would be influenced by different approaches to HCV screening and care.

e) the establishment and maintenance of a database of the treatment and care characteristics of all persons entering HCV specialist services.

3. Research

The APCG will identify priorities for research – particularly that aimed at improving the delivery of HCV-related health care and health protection services.

Key Epidemiological Facts

The Characteristics of HCV Infection

Diagnosis and transmission

- It is estimated that around 200 million people worldwide are infected with the Hepatitis C Virus (HCV).
- HCV was identified in 1989 and an antibody test to detect its current or past presence became available in 1991; to detect current infection a PCR test is used.
- In Scotland, following the introduction of heat treatment of blood factor in 1986, and the screening of blood donors in 1991, persons have not been at risk of acquiring HCV through the receipt of blood/blood factor.
- In resource-rich countries, HCV is mainly transmitted among injecting drug users who share injecting equipment though, occasionally, infection is spread through sexual intercourse or from mother to child during pregnancy or at the time of birth. HCV, relatively rarely is acquired through the use of unsterile sharp equipment in healthcare and non-healthcare (e.g. tattoo parlour) settings .
- In resource-poor countries, HCV is mainly transmitted through the receipt of infected blood/blood products and through the re-use of unsterile needles and syringes for healthcare purposes.

Natural history and treatment

- Less than 10% of infected persons experience an acute symptomatic illness.
- 25-30% of infected persons spontaneously clear their virus shortly after becoming infected.
- 5-15% of infected persons develop cirrhosis of the liver within 20 years of infection; factors associated with more rapid disease progression are older age at time of infection, male gender, excessive alcohol consumption and co-infection with HIV.
- People with longstanding infection may ultimately develop liver failure and/or liver cancer
- Infected persons who take a course of pegylated Interferon and Ribavirin therapy have a 50-60% chance of achieving a sustained clearance of HCV from their bloodstream; the rate is lower and higher for people with subtypes 1 and 3 (the most common types in Scotland), respectively.
- The National Institute for Clinical Excellence considers HCV antiviral therapy cost effective and the British Society for Gastro-enterology recommends that infected persons who have progressed to moderate Hepatitis and have no contraindications to treatment should be offered it.

The Epidemiology of HCV infection in Scotland

Prevalence and incidence of infection

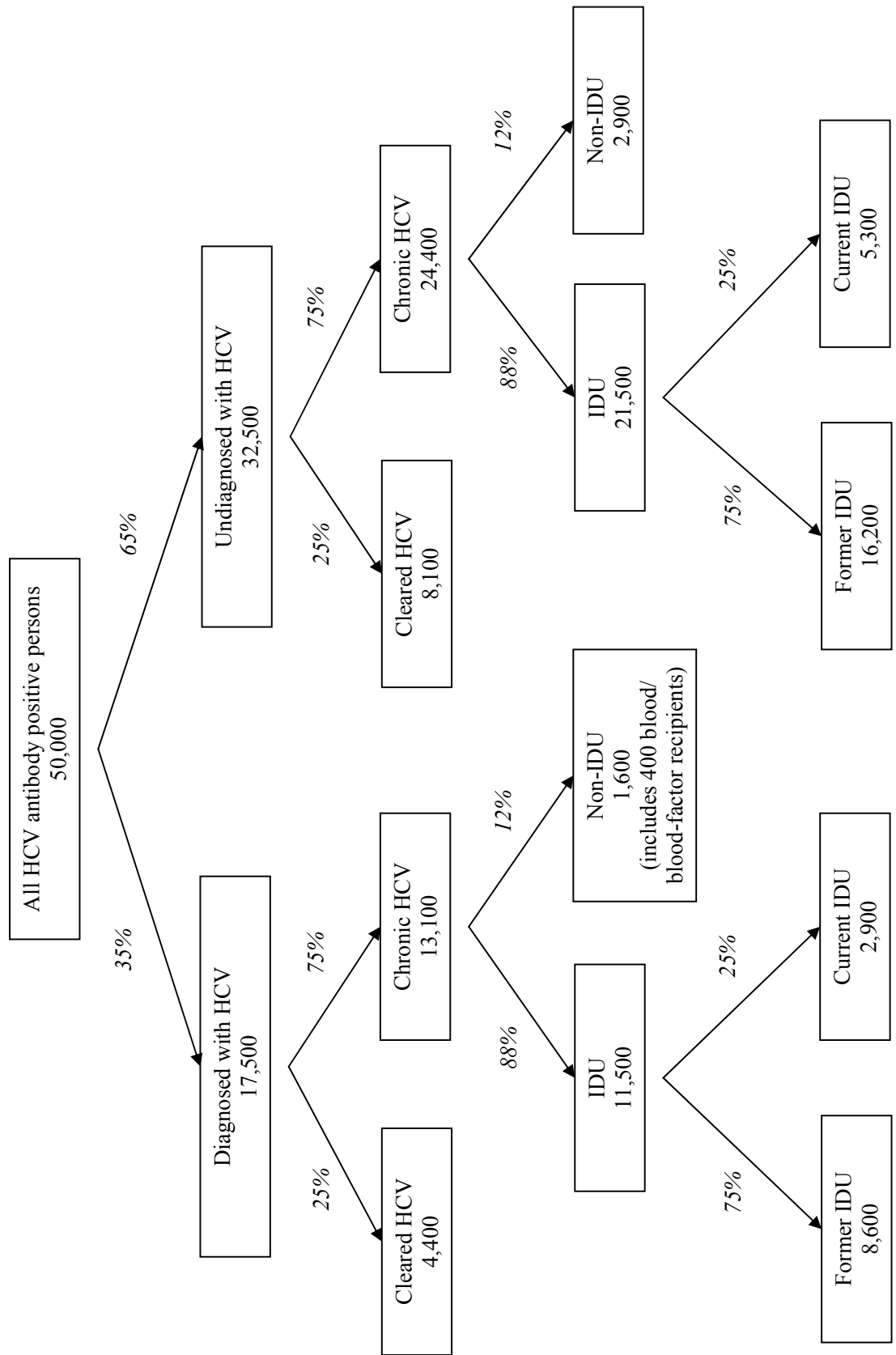
- The probability of having been infected with HCV is: 1 in 2-3 for current IDUs, 1 in 1.5-2 for former IDUs, 1 in 5 for prisoners, 1 in 200 for pregnant women and non-IDU genito-urinary clinic attenders, 1 in 500 for healthcare workers including surgeons, and 1 in 2500 for new blood donors.
- Between 1000 and 2000 IDUs are acquiring HCV annually; the problem is particularly acute in Greater Glasgow where the annual incidence is 20-30%. In some areas, including Lothian, the incidence of HCV among this population is considerably less. Among longstay prisoners who report ever having injected drugs, the annual incidence of HCV is approximately 10%.
- Approximately 10 babies are infected with HCV annually.
- No transmissions of HCV between healthcare workers and patients have been identified.

Estimates of numbers of persons infected as at 2004 (Figure 1).

- 50,000 living persons have been infected with HCV - a prevalence of 1%; this compares with around 0.5% for the rest of the UK.
- Approximately one-third of infected persons reside in Greater Glasgow, one-third in Lothian, Grampian and Tayside, and one-third in the other Health Board areas; two-thirds are male; the great majority are aged less than 50.
- Of the 50,000 persons, as above, 37,500 are HCV carriers (i.e. chronically infected with HCV).
- Of the 37,500 HCV carriers, 13,100 (36%) have been diagnosed; note that approximately 20,000 infected persons have been diagnosed but, of these, around 2500 have died and 4400 have spontaneously cleared their virus.
- Around 5000 diagnoses have been seen by a specialist in HCV infection and, of these, about 1000 have received antiviral therapy.
- Of the 37,500 HCV carriers, 24,800 are former and 8,2000 current IDUs .

See Figure 1

Figure 1: Approximate numbers of diagnosed and undiagnosed HCV antibody positive persons living in Scotland, 2004



Current and future disease burden

- Of the 33,000 ever injector HCV carriers, 22,800, 8,400 and 1,800 have mild, moderate and severe (cirrhosis) disease, respectively.
- Assuming current levels of HCV transmission and treatment uptake, it is predicted that in 2020, 19,000, 18,000 and 3,000 ever injectors will have mild, moderate and severe disease, respectively.
- Approximately 1200 persons had developed HCV (+/- alcohol) related liver failure during the years up to 2004.
- Assuming current levels of HCV transmission and treatment uptake, it is predicted that by 2020, 3200 persons will have developed HCV (+/- alcohol) related liver failure.

The data on the Epidemiology of Hepatitis C in Scotland were generated by epidemiologists at Health Protection Scotland and the MRC Biostatistics Unit, Cambridge, in association with clinical and virological colleagues They are detailed in the following three papers which are being considered for publication in scientific journals. If further information is required, please contact Dr Sharon Hutchinson at HPS (sharon.Hutchinson@hps.scot.nhs.uk ; 0141 300 1103)

- Hepatitis C virus infection in Scotland: Epidemiological review and public health challenges. Hutchinson SJ, Roy KR, Wadd S, Bird SM, Taylor A, Anderson E, Shaw L, Codere G, Goldberg DJ.
- Hepatitis C Virus infection among injecting drug users in Scotland: A review of prevalence and incidence data and the methods used to generate them. Roy KM, Hutchinson SJ, Wadd S, Taylor A, Cameron S, Burns S, Molyneaux P, Macintyre P and Goldberg DJ.
- Modelling the Current and future disease burden of hepatitis C among injecting drug users in Scotland. Hutchinson SJ, Bird SM, Goldberg DJ.

**Analysis of responses from key stakeholders on
Scotland's top priorities for action on
Hepatitis C**

**The Scottish Executive on behalf of the
Chief Medical Officer for Scotland**

22 April 2005

Summary

In February 2005, the Scottish Executive invited a wide range of stakeholders in Scotland to set out their **three top priorities for action** to address the prevention and management of Hepatitis C. The responses were collated and analysed, and the following priorities for action were identified:

Prevention

- Increase the availability and accessibility of needle exchange services.
- Develop more — and more effective — outreach services for injecting drug users (IDUs).
- Target drug users at an early stage in their injecting career, and indeed, before they begin to inject. Interventions among vulnerable young people, in particular, are seen as a priority.
- Identify, treat and change behaviour among IDUs who may already have the Hepatitis C virus (HCV).

Testing

- Provide greater access to testing.
- Identify those who are at risk (in particular, former and current IDUs and their partners) and increase the numbers coming forward for testing.
- Persuade patients and professionals of the benefits of knowing one's HCV status.
- Enhance laboratory services to manage the increase in uptake for testing.

Treatment

- Improve the accessibility of treatment — and reduce the barriers to people who seek treatment.
- Provide appropriate and adequate staffing for treatment.
- Improve service integration to encourage seamless working — between primary and secondary care, between doctors and nurses, between different groups of specialist consultants and between health and social care professionals.

Education and awareness

- Raise awareness and improve educational initiatives among current IDUs
- Educate and raise awareness among professionals — in particular, GPs and pharmacists.
- Raise awareness among the general public to help identify the large numbers of people who are HCV-positive but unaware of their status.
- Increase awareness among elected representatives of the importance of needle exchange.

Resource allocation

- Provide adequate financial resources for testing and treatment.
- Increase funding for needle exchange.

Strategic planning and commissioning

- Develop an integrated strategy for preventing and managing blood-borne viruses — a new Scottish Blood-borne Virus strategy.
- Establish and support surveillance and monitoring systems that can help in the planning and targeting of services.

Other priorities

- Ensure that methadone treatment programmes are working to a high quality standard and optimum effectiveness.
- Provide greater access to primary care for IDUs.
- Prevent and appropriately manage needlestick injuries.
- Ensure rigorous instrument decontamination.

Introduction

In February 2005, the Scottish Executive invited a wide range of stakeholders in Scotland to set out their **three top priorities for action** to address the prevention and management of Hepatitis C. This invitation was sent to, among others:

- Directors of Public Health;
- Scottish General Practitioners Committee;
- representatives of Drug Action Teams;
- AIDS/BBV coordinators in NHS Boards; and
- the Chairs of NHS National Services Scotland, the Scottish Viral Hepatitis Group and the Scottish Association for Medical Directors.

Invitations were also sent to a number of charitable and voluntary organisations responsible for information or support activities related to Hepatitis C. The responses would be used to inform the development of the Hepatitis C Action Plan for Scotland.

Twenty-one responses were received from 22 individuals. (One response was signed jointly by two people. A list of the respondents and their affiliations is given in Annex B.) The respondents represent 15 NHS organisations, four voluntary / charitable organisations and two local authorities.

The main priorities for action were identified as:

- Prevention
- Testing
- Treatment
- Education and awareness
- Resource allocation
- Strategic planning and commissioning
- A small number of other priorities

A full analysis of the responses is presented below. Given the small numbers involved, no attempt has been made to compare the submissions of different types of respondents (for example, comparing comments from public health consultants to those of others). Similarly, comments have not been ranked in any way on the basis of the respondent's role or affiliation, nor have they been weighted on the basis of whether the response was a personal response or a response on behalf of an organisation or group. If a particular issue seemed to be important to a number of respondents, this is indicated.

Prevention

In general, respondents felt that there was a need to **increase the availability and accessibility of needle exchange services** — and to massively increase the availability of sterile needles and paraphernalia (citric acid, filters, spoons, etc.) within those services. The accessibility of services should be improved not simply by providing services in geographical localities where none currently exist, but also through expanding opening hours, and exploring the possibility of offering facilities such as vending machines. The distribution of paraphernalia was seen to encourage greater use of needle exchange services by IDUs, and therefore should be made more widely available.

Related to this was a view that **more — and more effective — outreach services for IDUs** should be developed. However, these services should be **in addition to — not instead of —** the expansion of fixed site needle exchanges. One suggestion was to increase the number of services delivered by community pharmacies. However, this was offset by a comment that community pharmacies should be taking on a more pro-active public health role than they currently do, and that those who provide needle exchange services (particularly community pharmacists) should be appropriately trained for this role.

Another priority was the need to target groups **at an early stage** in their injecting career — or even more important, targeting them **before they begin to inject**. Innovative and effective interventions are needed among vulnerable young people and problem drug users who are considering or just embarking upon an injecting career. Such interventions need to bear in mind the chaotic lifestyles and possible poor health and literacy skills within this population.

There was also a common view that there needs to be an increase in activity among professionals to **identify, treat and change behaviour** among IDUs who may already have HCV or be at risk or acquiring it. Screening should take place not only in drug treatment services, but in other settings such as hospitals and prisons. Those who are identified as having high-risk practices should be linked to nurses who would be able to discuss safer injecting practices and HCV testing, and provide vaccination, appropriate counselling and referral to treatment and advice services.

Improved education, targeted health promotion interventions, and public information campaigns were seen as important tools in preventing the transmission of HCV. These are discussed in more detail under the section **Education and Awareness Raising**.

Testing

Testing was seen as crucial — not only in identifying people who might benefit from treatment, but also in preventing further transmission of the virus. In general, respondents felt that there was **a need for much greater access to testing**, and that this testing must include high-quality pre- and post-test counselling. It was clear from the responses that this is a particular problem in some geographical areas of Scotland. However, as one respondent pointed out, accessibility is not just about geography — accessible services are those which are also “acceptable” to the groups they are targeting.

There was a view expressed that testing should not simply be *made available* to individuals, but that people should be *positively encouraged* to take the test, and that priority should be on **identifying at-risk people** (in particular former and current IDUs and their partners) **and increasing the numbers** who come forward for testing. One respondent suggested that clarity was needed about the most effective way to undertake active case finding among former IDUs.

Connected to this, was a need to **persuade both patients and professionals** that there are medical and personal benefits to knowing one’s HCV status. In general, respondents felt that more needed to be done to educate health professionals on this subject. Once again, specialist HCV (or BBV) nurses were seen as having a crucial role in the area of testing. Nurse-led services (both hospital and community based) were proposed as a possible model for improvements in this area.

It is clear, however, that a more pro-active approach to testing would have a knock-on effect for existing testing and treatment services. The point was made that **laboratory services would need to be enhanced** to manage the increase in uptake for testing. In addition, staff and treatment services would have to be prepared — and this may involve further education and training of health and social care professionals. This issue is discussed in more detail in the section “**Education and Awareness Raising**” below.

Treatment

In general, the main priority for treatment was to **improve the accessibility of treatment**. And once again, it was clear that certain geographical areas of Scotland currently have significant problems in this respect and that these need to be addressed as a matter of urgency. In some areas, there simply are no services available. Patients from these areas are required to travel great distances for treatment, and little support is provided locally during their treatment. This situation results in high default rates — and thus wasted resources. In other areas, there are long waiting lists — the waiting lists for liver biopsy was mentioned as a particular example.

It is clear, however, that the issue of accessibility goes far beyond the issues of geography and waiting lists. There is a general need to “reduce the barriers to treatment for IDUs” — and as one respondent said, this includes the need to persuade health professionals of the benefits of HCV testing and treatment. The view was expressed that if HCV-positive individuals were treated sooner, it would avoid the need for additional resources and further care systems at a later date. However, several other respondents pointed out that if a concerted effort is made to identify individuals who are currently infected but not diagnosed, then the demand for treatment would inevitably grow. The necessary infrastructure has to be in place first to support patient care.

In discussing the problem of accessibility, a number of respondents proposed some solutions. Views largely focussed on two main issues.

Appropriate and adequate staffing were seen as key, and many respondents advocated greater use of specialist BBV nurses. These nurses could work within a hospital setting (for supervising treatment), but could also undertake vaccination and carry out testing in primary care (through local BBV clinics), prison and outreach settings in the community. They could also work closely with specialist drug treatment services to supervise anti-viral treatment for those who are on methadone programmes. One respondent suggested that delivering HCV treatment in the same location as methadone maintenance programmes would improve adherence to HCV treatment. Another suggested that community-based treatment services, provided by nurses working with proper access to a consultant, could offer an important new way of deflecting pressure from acute services.

Better service integration was also seen as crucial. Respondents talked about the need to remove “boundaries” and encourage “seamless working” — between primary and secondary care, between doctors and nurses, between different groups of specialist consultants, and between health and social care professionals. One respondent proposed adopting a ‘Managed Service Network’ model (i.e., not simply a ‘Managed Clinical Network’). This Managed Service Network would integrate a range of specialist services at a local level (psychologists, dieticians, clinical services, drug services and other support services). Another suggested

creating an “integrated harm reduction service” which could combine elements of existing harm reduction services with genito-urinary medical services, primary care and dental care services. Yet another suggested that there needed to be better partnership working between agencies and organisations concerned with HCV and those concerned with sexual health and HIV. While the details of these proposed solutions varied between respondents, it is clear that many saw the need for better service integration in relation to HCV treatment as a very high priority.

One individual suggested that access to treatment should be based on research of clinical and cost effectiveness.

Education and awareness-raising

There was a general view among respondents that there is a great deal of ignorance about the subject of Hepatitis C — not only among those who have or are at risk of acquiring the virus, but also among health and social care professionals who have (or could have) a vital role in prevention and treatment. Therefore, the need to raise awareness among these groups was seen as an important priority.

Raising awareness and changing behaviour among current IDUs was seen as key to preventing transmission of the virus. A number of respondents called for more and better educational initiatives among IDUs — taking into account, as mentioned above, the chaotic lifestyles and possible poor literacy skills among this population. Respondents felt that IDUs needed greater access to information about HCV and options for treatment, and it was suggested that there should be an increase in the provision of services in the statutory and voluntary sector that can provide specialist information on this subject. Another respondent expressed the view that families and carers of IDUs potentially have an important role in preventing onward transmission of Hepatitis C, and that it could be beneficial to provide these individuals with training, education and support regarding HCV.

The need to **educate and raise awareness among professionals** — and in particular, GPs and pharmacists — was also seen as a very high priority. Respondents mentioned specifically the need to make appropriate educational materials available to GPs, and the need for training for other health professionals and support staff.

One individual called for an audit of the current training and education of health professionals on the subject of hepatitis C. The purpose of such an audit would be to establish whether and how this subject is covered in existing curricula and educational materials, and then to develop training plans to fill the gaps. It was clear that other respondents saw the lack of awareness about HCV among health professionals as one of the barriers to receiving adequate treatment.

Less commonly, respondents also highlighted the need for a **public awareness campaign**. The purpose of a such a campaign should be to identify the large proportion of HCV+ people (estimated at approximately 70%) whose infections are currently undiagnosed. There was a suggestion that this campaign should be across all media, including cinema, TV, radio and print, and that it should be on-going — not a one-off event. There was also a suggestion that the public profile of HCV should be raised through including lessons about it in school and college curricula. One individual pointed to a specific need to **increase awareness among**

elected representatives of local councils of the crucial role of needle exchange services in preventing and reducing transmission of hepatitis C.

Resource allocation

The importance of **adequate financial resources for testing and treatment** was raised as a general concern by the respondents. Many pointed to a considerable year-on-year increase in treatment costs, and suggested that the NHS was inadequately resourced to manage a growing number of HCV-positive patients. Some indicated that efforts to identify individuals who had the virus, but who were undiagnosed, would merely exacerbate this situation. Respondents expressed frustration that HCV is a recognised public health priority, but it appears not to be highly ranked for service developments. Some individuals called for resources for HCV prevention and treatment to be allocated on the basis of estimated HCV prevalence in the population. Another felt that funding decisions, and mechanisms for obtaining funding, must be flexible to reflect the fact that a “one-size-fits-all” model is unlikely to be successful in Scotland.

One individual suggested that there should be ring-fenced monies for HCV therapy, just as there are currently ring-fenced monies for prevention. However, another respondent argued against this, pointing out that the division between “prevention” and “treatment” monies was unhelpful, given that the same staff tend to be involved in both prevention and treatment activities.

While increased funding for treatment appeared to be the greater concern, respondents also highlighted a need for **increased funding for needle exchange** — to allow for distribution of a greater number of needles, as well as the distribution of paraphernalia such as citric acid, filters and spoons.

Strategic planning and commissioning of HCV services

In relation to the discussion of resource allocation, a number of respondents pointed to the importance of developing **an integrated strategy for preventing and managing blood-borne viruses**. The view was expressed that a new Scottish BBV strategy was needed, and that this should be linked to other existing strategies and frameworks, including the Sexual Health Strategy, Scotland’s Health at Work, Health Promoting Schools, etc. As mentioned above, respondents seemed frustrated at the lack of priority given to service developments in this area, and there was a suggestion that existing services lack integration and, in some areas, are not sufficiently patient-focused.

Surveillance and monitoring were seen as key activities. It was felt that a reliable, properly-funded, national system of collecting data, particularly data on IDUs, was needed to inform the planning and targeting of services. Any surveillance system should allow for the reporting of incidence, prevalence, patient demographics and treatment outcomes on a routine basis, by Health Board area. One individual felt that the system should also incorporate behavioural data. There was a suggestion that the Scottish Hepatitis C Action Plan, like its English counterpart, should require the production of an annual report to monitor whether and how the Plan is working.

Other priorities for action

A small number of other priorities for action were mentioned, which do not fit easily into any of the categories described above — although, these issues are perhaps related to HCV prevention. These included the need to ensure that methadone treatment programmes are working to a high quality standard and optimum effectiveness; the need to provide greater access to primary care for IDUs; the need for needlestick injury prevention and management; and the need for rigorous instrument decontamination.

Annex A: Respondents

- **Dr David Breen**, Consultant in Public Health Medicine, NHS Dumfries and Galloway
- **Scott Bryson**, Pharmaceutical Adviser and Chairman, Hepatitis Treatment & Care Group, Greater Glasgow NHS Board
- **Dr Catherine Chiang**, Consultant in Public Health Medicine, NHS Argyll & Clyde
- **Grahame Cronkshaw**, Strategic Manager, Drugs and Alcohol, NHS Grampian
- **Alex Davidson**, Head of Adult Services, South Lanarkshire Council
- **Tom Divers**, Chair of Greater Glasgow Drug Action Team
- **Philip Dolan**, Chairman, Scottish Haemophilia Forum
- **Lucy Eagles**, Specialist Pharmacist in Substance Misuse, Woodend Hospital, Aberdeen
- **Charles Gore**, Hepatitis C Trust
- **Wendy Hatrick**, Public Health Nurse, NHS Shetland
- **Dr Helen Howie**, BBV Co-ordinator and Chair of the Grampian BBV Group
- **Dr Nick Kennedy**, Consultant, Infectious Diseases Physician and Clinical Lead, Lanarkshire HIV, AIDS and Hepatitis Centre, Monklands Hospital
- **Dave Liddell**, Director, Scottish Drugs Forum
- **Tina McMichael**, Health Improvement Officer, Sexual Health & BBVs, NHS Ayrshire & Arran
- **Dr Peter R Mills**, Consultant Physician and Gastroenterologist, Gartnavel General Hospital, NHS Greater Glasgow
- **Dr Dorothy C Moir**, Director of Public Health, Lanarkshire NHS Board
- **Dr Bill Mutch**, Medical Director, Primary Care Division, NHS Tayside, Ashludie Hospital
- **Dr Ken Oates**, Acting Director of Public Health, NHS Highland
- **Robert Peat**, Director of Social Work and Health, Angus Council
- **Jacqui Pollock**, HIV-AIDS Carers & Family Support Group
- **Kay Roberts**, SACDM Member and Co-ordinator of Greater Glasgow Pharmacy Needle Exchange, NHS Greater Glasgow
- **Nicola Rowan**, Manager, UK Hepatitis C Resource Centre
- **Liz Scotney**, BBV Nurse, NHS Dumfries and Galloway
- **Rosina Weightman**, Primary Care Nurse Facilitator, NHS Lothian Primary and Community Division



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