Hepatitis C among people who use drugs: Key messages from practitioners

Correlation working group on Hepatitis C

Colophon:

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ISBN/EAN: 978-90-812297-0-8

Publisher

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Layout: s-webdesign

Correlation is co-funded by the European Union under the programme of community action in the field of public health 2008 - 2013 and the Dutch Ministry of Health, Welfare and Sport (VWS).

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Abbreviations

HCV	Hepatitis C Virus
HBV	Hepatitis B Virus
HIV	Human Immunodeficiency Virus
IDU	Injecting Drug User
NGO	Non-Governmental Organization
BBV	Blood-Borne Virus
MCN	Managed Care Network
AIDS	Acquired immune deficiency syndrome
APDES	Agência Piaget para o Desenvolvimento (Piaget Development Agency)
IHRA	International Harm Reduction Association
NHS	National Health Service
INPUD	International Network of People who Use Drugs
WHO	World Health Organization
UNODC	United Nations Office on Drugs and Crime
ARUD	Arbeitsgemeinschaft für risikoarmen Umgang mit Drogen; The Association for Risk Reduction in the Use of Drugs
STI	Sexually Transmitted Infection
SVR	Sustained Virological Response

Introduction

The increasing burden of hepatitis C, particularly among people who inject drugs, requires comprehensive, well balanced and targeted policy and practice. The burden of hepatitis C remains underestimated by many policy makers, professionals and the public. There is, however, considerable evidence and expertise upon which guidance for effectively tackling hepatitis C in Europe can draw.

The key messages included in this report represent the most important aspects of interventions targeting injecting drug users. These have been identified through field work, the day to day experience of practitioners and a literature review. Starting with approaches to prevention, such as awareness and training, the messages go on to describe the most important elements of service delivery including monitoring, testing and improving access, all with an essential focus on the involvement of patients and service users. As all interventions work best embedded in a national action plan or strategy, this report closes with a brief examination of what makes these most effective.

Each individual message describes an action needed to improve the local or national response to hepatitis C, including the central guiding principles and key components of the approach. One or two examples, selected based on a set of common criteria, describe existing interventions for the particular topic. A reference section and suggestions for further reading complete the overview of each key message. Inevitably, many of the messages are related and depend upon the wider framework of interventions in place.

The selection of the messages included focused on information directly relevant to hepatitis C and (injecting) drug use. Most of these messages are also relevant for other communicable diseases, however, such as HIV and for public health in general. At the same time HIV- or public health-related recommendations and research findings are likely to provide useful insights which are or should also be applicable to hepatitis C.

Messages relevant to drug and health policy in general have not been included in this report. Specific attention is needed for vulnerable people including drug users because of the lack of accessible treatment and care, and the need to fight stigma, discrimination and marginalization. This need occurs everywhere, and forms a baseline from which all policies, strategies, services and interventions must advance if hepatitis C is to be effectively tackled in the world today.

Good Practice Criteria

Prevention and health promotion, especially for socially disadvantaged people and groups, are high on current national and international policy agendas. Restrictions in time, money and manpower, however, mean there is an urgent need for effective strategies and interventions in this field; decision-makers, actors and the public require evidence-based and scientifically investigated interventions.

Professionals in health prevention and promotion always face an array of challenges in developing the methods, instruments and procedures which improve the quality of interventions. Creative and innovative approaches are vital to improve provision, but require a degree of testing and experiment, while the modern holistic approach to health encompasses far more than could ever be addressed through a single intervention. Increasingly integrated, 'setting based' services require complex evaluation. It is for these, among many other, reasons that a basic set of quality criteria specifically for health promotion among socially disadvantaged groups has been identified.

As with all of the material included in this report, the below criteria were collated using an inductive approach to assess and collate practitioners' 'practical expertise'. This was initiated and undertaken by Euro Health Net in collaboration with an EU consortium on the socio-economic determinants of health. The list produced constitutes an initial attempt by practitioners to identify key criteria for identifying models of good practice. Below these are described in summary as reference for readers of this report; full details of the consultation process and the full definition agreed for each criterion can be found at the German Health Institute website www.gesundheitliche-chancengleichheit.de (German) and the Closing the Gap website www.closing-the-gap.org

Criteria to determine models of good practice

Quality elements	Leading questions for the assessment
Needs assessment The intervention has analyzed the needs of the target group and of actors and organizations involved.	• How have the needs been analyzed (e.g. epidemiological statistics, professional expertise, consultation of target group)? • How is the needs assessment linked to the design of the intervention?
Low barrier method The intervention is accessible and outreaching and it takes account of physical and economic environment making healthy choices easier.	• How do practitioners contact the target group? • In how far are communication barriers (including culture, language, 'agenda') considered in the intervention?
Participation and commitment of the target group The concept of participation can mean different things. According to type and scope of the intervention, composition and motivation of the target group, different forms of participation can be beneficial and necessary - or even too demanding and repressive. Participation includes • formulation of desires, needs and criticism, • participation in decisions, • participation in making rules or • active inclusion of all persons effected in the planning, implementation and evaluation of the offers.	• Have organizations, groups and/or individuals concerned been given the opportunity to participate in decision, planning, implementation etc? • How do you attempt to foster participation?
Empowerment of the target group Empowerment is the process of encouraging and enabling people to arrange their living conditions to promote health.	• How does the intervention enable the target group to master own problems? • Has the target group been provided instrumental help (money, space)?

Setting approach The term 'setting' refers to a social system (company, school, hospital, city district etc.) in which people pursue every day activities. Setting oriented interventions are aimed at the socio- structural conditions of the setting and the group of people involved	• How are existing communication structures, decision processes and rules influenced? • A setting intervention tries to improve health indirectly by creating a health promoting live world. How does the intervention realize this and in how far does it ultimately improve health?
Collaborative capacity building / partnership A collaboration between different persons, institutions or sectors has been built to take action on health or intermediate outcomes.	• Which type of collaboration has there been with regard to planning or implementation of the intervention? – Partnership – Service agreed upon – Collaboration of public authorities – Multisectoral collaboration – Multidisciplinary collaboration – Collaborative planning – Teams • How do these partnerships contribute to the effectiveness and efficiency of the intervention?
Snowballing / intermediaries concept Snowballing is a way to multiply the skills and knowledge required for the project rapidly by 'training-of-trainers'. These trainers, i.e. intermediaries, work as a role model to provoke the desired behavior in the target group.	• How have intermediaries been selected? • Are intermediaries motivated, accompanied and qualified in the intervention?
Quality management (QM) Quality management is a continual improvement process. This means that quality is not viewed as a value that has been achieved once but is continuously checked, improved and developed in all areas (structure, process and outcome quality).	• Is there a QM system applied to ensure and develop quality such as DIN ISO 9001? • Which quality assuring structures have been created such as: externally evaluated study design, operation manual, qualification of personnel, development of organizational and communication structures (working groups, committees) etc.?

Evaluation Evaluation is an analytical process to assess a project's structures, processes and outcomes.	• Which methods have been applied for the evaluation of the intervention? • Has the evaluation had impact on structures, processes and outcomes of the intervention?
Proportionality The intervention must have a balance in re-sources, timing, scale, cost-benefit, etc.	• Are there indicators that document the efficiency of the intervention? What are these? • Is the intervention deliverable within the time- scale appropriate for user group's needs?
Sustainability The intended effect of the intervention persist after it has finished or for ongoing projects: You have good reason to expect that the results will persist".	• Does the intervention start a mechanism that can continue a support the outcomes of the project after it is finished? • Is there routine to monitor the results after the project is finished?

Key Message 1:

"Raise awareness of blood"

Blood awareness means understanding the potential for blood to contain blood borne pathogens as well as understanding how these can, and cannot, be transmitted. The promotion of blood awareness is a key strategy for preventing the spread of blood borne viruses and promoting essential hygiene measures where blood may be present.

It is an attitude and an essential component of all programs, procedures and practices designed to prevent transmission of HIV, hepatitis C and other blood borne viruses.

Blood Awareness is especially important for people who have direct contact with blood, such as medical personnel and injecting drug users, but at the same time to avoid new infections relevant information should be made available to the whole population.

Guiding principles for blood awareness interventions:

1. Blood awareness must be recognized as an important and indivisible part of infectious disease prevention at all levels.
2. The awareness message should be developed for different groups, considering the specific needs of each, the risks they face, appropriate language and effective means of communication.
3. Awareness messages need to be prepared collaboratively, involving specialists in different areas (for example medical personnel, members of the target group, NGOs, government).
4. The promotion of blood awareness must be approached in a way that promotes inclusion and does not perpetuate stigma towards people who use drugs or those with hepatitis C.
5. Careful consideration of how messages are delivered as well as who they are delivered by is essential. Peer-led or community interventions, for example, may be more effective in some contexts while information from experts may work better for other target groups or messages.

Key components of effective blood awareness interventions:

Empowerment of the target group: Blood awareness messages must empower the target groups to adopt healthier lifestyles and promote safety across society. The target group must be clearly identified. Messages should be prepared specifically for each group, with their involvement.

Needs assessment: Research and needs assessments should inform the development of all messages and interventions.

Evaluation: Ongoing monitoring and evaluation activities are vital to determine the effectiveness of campaigns. Where possible, identifying changes in rates of diagnosis, testing, treatment and care, as well as the adoption of healthier lifestyles, will provide important insights for improvement and replication.

In practice:

England: Assessing and addressing blood borne viruses

'Be Blood Aware' is a face-to-face awareness tool developed by UK NGOs Addaction and Mainliners. It aims to raise awareness of blood borne viruses among the general population.

The tool assesses participants' existing knowledge of BBVs and 'fills in the gaps', with an emphasis on specific risks that the participant is more likely to be exposed to. It is therefore very flexible and can be adapted to, for example, a prison health event or a university fair and delivered by drug or health specialists or as a peer-to-peer intervention. The focus is on educating people so that they can change their behavior, empowering them to manage their own risks in future and improving general knowledge and understanding of BBVs.

Australia: Online support for young people

'Get The Facts' is a website developed by the Western Australia Department of Health. It provides information and support on a range of issues that affect young people in the state.

The website includes educational materials developed specifically for young people, using a range of creative approaches to disseminate information on sexual health, blood borne viruses and relationships as well as topics such as drugs and alcohol. As a part of the education program a dedicated video about BBVs has been created which provides simple, clear messages on how these can, and cannot, be transmitted and how risks can be avoided.

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Key Message 2:

"Raise awareness of hepatitis C"

Raising awareness of hepatitis C and how it is, and is not, transmitted can enable people to know whether they have been at risk while also reducing the stigma often associated with the virus.

For up to a third of people who have hepatitis C the transmission route is not clear so it is vital to raise awareness among the general population (1). Specific work to target higher risk groups is vital too, however, to reduce rising global prevalence. Through earlier diagnosis this can also increase the likelihood of successful treatment for more people.

Guiding principles for hepatitis C awareness interventions:

1. Campaigns should be embedded in wider prevention plans, for example those for tackling other blood borne viruses and drug misuse.
2. Promoting desired behavior as the norm, not an exception, will improve effectiveness as people naturally tend to conform to the group.
3. Goals and target groups must be clearly identified through needs assessments.
4. Campaigns should provide information about risks and the precise steps that can be taken to reduce these.
5. People who think they may have been at risk need to have the opportunity to get tested and, where necessary, to access treatment.
6. Communication has to use varied methods and forms in order to reach the specific target groups effectively.

Key components of effective hepatitis C awareness interventions:

Needs assessment: For an effective awareness campaign it is essential to know your target group. Through a needs assessment the risks in the local context can be clearly understood, target groups are identified and opportunities to communicate with them most effectively can be selected.

Participation and commitment of the target group: Communication campaigns are more successful if they are tailored to the context, values, language, and existing knowledge of the target group. To understand this it is important to involve them in the development of campaigns.

Evaluation: Embedding evaluation in program design helps to formulate specific, relevant goals and to plan how the effectiveness of a campaign is measured. Later, documentation and evaluation can help improve service effectiveness as well as providing evidence for designing future interventions.

In practice:

England: Raising awareness and tackling stigma

The 'FaCe it' campaign was launched in 2006 by the UK Department of Health. It aims to raise awareness of hepatitis C among healthcare professionals and the general public, while also tackling stigma.

Local needs assessments were conducted to look at specific target groups and the right messages for them. A series of benchmarks were then developed to continuously measure progress against the campaign's objectives. It used diverse methods of communication, including a photography exhibition road show, a CD resource for young offenders' services and a DVD aimed at prisoners and prison health workers.

Positive outcomes included an increase in testing and improved knowledge of hepatitis C among the general public. Following evaluation, improvements have been made to the campaign, including greater collaboration with stakeholders, more use of peer-to-peer approaches and the use of real-life case studies.

The Netherlands: Tailored and general awareness messages

In the Netherlands, The National Health Council identified a need for greater hepatitis C awareness and highlighted this to the national government. Since robust prevalence data were unavailable, the campaign was aimed at the general population as well as likely higher risk groups such as (injecting) drug users and intermediaries such as GPs and professionals from health and addiction care.

The campaign 'Hepatitis C. Heb ik het ook?' (Hepatitis C, do I have it too?) was initially piloted in three regions, and the evaluation of each was used to inform the national roll-out. Where needed, materials and approaches were revised and then finally re-tested before implementation across the country.

Specific methods and materials were developed to reach each target group. For drug users, a game called Russian Roulette was created for use by outreach workers. Migrant groups were also engaged face-to-face while materials including flyers, t-shirts, websites and advertorials were developed for other target groups and the general public.

The central outcome of this work was an increase in the amount of tests taken and a higher percentage of positive test results. The methods used, evaluations and results have been published and disseminated (2, 3).

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Key Message 3:

"Train the workforce"

Professionals such as health care providers and drug service workers are uniquely placed to help raise awareness among at risk groups, encourage testing and treatment and to provide comprehensive support. They need to be trained to identify people at risk of infection and qualified to increase diagnoses and the uptake of treatment.

Training can motivate and inspire and through broadening the knowledge and skills of the personnel involved will strengthen the organization. As factors such as counseling methods or levels of attention to certain diseases frequently change, ongoing learning and training is essential to maintaining and developing this strength and to improving whole systems.

Guiding principles for workforce training programs:

1. What needs to be done and/or changed to improve attention to hepatitis C prevention, screening and treatment will differ from organization to organization.
2. Training should support the organizational, structural and personal needs of staff to strengthen existing good practice and to allow change.
3. Follow the training cycle: research needs, formulate goals and content, prepare and offer the training and then follow-up and evaluate each module or part.
4. Training must be tailored to maximize its relevance to the target workforce: the needs of drug workers will differ from those of people working in health services.

Key components of effective training programs:

Participation and commitment of the target group: Inspiring trainees' enthusiasm and helping them understand the importance of addressing hepatitis C is a vital first step. Staff commitment and motivation need to be maintained to effectively reach IDUs; involving all target groups in the development of training programs will make them more effective both for the workforce and for their patients or service users.

Evaluation: Training should be developed in ways that facilitate assessment and replication. Work should be evaluated and results should be used to make improvements. As far as possible successful materials should also be made available for use by others.

Snowballing / Intermediaries concept: Training (including 'train the trainers') is often one of the first steps in implementing an action plan and can also promote

professional commitment to an issue. It should therefore be easily available and accessible to all parts of the workforce which may benefit from it.

In practice:

The Netherlands: Comprehensive, stepped training programs
Mainline Foundation has developed a modular hepatitis C training program for professionals working with drug users.

Basic levels provide an insight into the symptoms, the course of the disease and treatment. This focuses on pre- and post-test discussion and on implementing a pro-active testing policy, including counseling to motivate people at risk to get tested.

The training was developed and provided in cooperation with experts in the design of prevention programs at the Trimbos Institute and with Bouman GGZ, an addiction care centre. The counseling training is delivered as a 'train the trainer' course to nurses specialized in infectious diseases and drug use. A third course, also developed with Bouman GGZ with support of the Ministry of Health, focuses on counseling during treatment. Part of this training cycle for professionals is a clinical session about hepatitis C, provided by a pharmacist or specialist.

All training is developed with input from drug users and professionals and are initially piloted, evaluated and, if necessary, adjusted. The training is embedded in the Dutch Hepatitis C Campaign 2009-2010 (see Key Message 2: Raise Awareness of Hepatitis C).

Europe: A collaborative training program to meet widespread needs
In 2010 the Correlation Network and the Eurasian Harm Reduction Network collaboratively initiated the development of a training program to improve hepatitis C treatment and care for injecting drug users. This will address the common training needs that the group has identified as existing in many European countries.

The training is comprised of a series of modules, allowing it to be tailored to local contexts, to the type of target group (policy makers, medical staff, advocacy organizations or harm reduction teams, for example) and to participants' existing knowledge levels. It is provided as a complete resource which includes all necessary information and materials for it to be delivered by local trainers, including comprehensive guidelines for them. Topics covered include hepatitis C transmission, hepatitis C testing, treatment options, lifestyle factors and the management of hepatitis C, co-infection with HIV, and advocacy for change.

Before it was finalized the training was piloted with 27 professionals from 13 countries. Their feedback, along with that of other reviewers was incorporated into

the final version. The training has been made freely available in English and Russian, to be used by trainers and experts in hepatitis C.

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Key Message 4:

"Young people at risk need dedicated, early interventions"

Innovative approaches that enhance young people's awareness and understanding of hepatitis C form an essential part of any prevention strategy. This is especially important for those at greater risk of engaging in higher risk behaviors.

For many, the period of transition into adulthood involves experimentation. A number of new experiences and behaviors including tattooing, body piercing and drug use are known to carry risks in relation to hepatitis C transmission.

It is therefore vital that young people can access balanced, relevant and meaningful information during this crucial period. Ideally information and interventions should be available prior to, or very early on in, the stages that risk taking behavior is likely to occur.

Guiding principles for reaching young people at risk:

1. Identifying young people and engaging them in a way that is appropriate to their needs is challenging. Involving a broad range of services with expertise in working with them - such as schools, youth clubs, and specialist services, as well as young people themselves – is essential.
2. Workers in these settings should be confident and competent to provide basic information and advice. Where appropriate they should also have an awareness of, and working links with, specialist services such as harm reduction and testing and treatment services.
3. To be most effective, workers need access to training and/or resources on hepatitis C to enable them to discuss issues in a sensitive, relevant and meaningful way with young people.

Key components of effective interventions for young people at risk:

Setting approach: Utilizing a broad setting approach ensures that the number of young people targeted can be maximized. The content and delivery styles used should also be tailored to the needs of each target group.

Collaborative capacity building / partnership: Vulnerable young people may be reluctant to access drug and healthcare services. Other sectors they engage with, including education, housing/homelessness, criminal justice, mental health and employability services must therefore play a role in raising awareness of hepatitis C.

Snowballing / Intermediaries concept: Providing training and/or resources on hepatitis C to workers from a range of sectors that engage with young people is essential. They must have the confidence and competence to cascade appropriate information. Varied approaches including brief interventions, one to one counseling and group work should be available as appropriate for the target groups.

In practice:

Scotland: Training voluntary organizations working with vulnerable young people
The Scottish Drugs Forum's National Hepatitis C Young Persons Intervention Project provided training on hepatitis C to workers in non drug specialist voluntary organizations that work with vulnerable young people.

Young people's services often engage with a sub-population at higher risk of involvement in IDU and consequent exposure to hepatitis C. This engagement occurs at a critical time when young people may be moving towards, or are in the early stages of, IDU. Provision of basic training on hepatitis C to this workforce enhances their ability to provide relevant information and advice.

The training has three main aims: (1) to encourage these services to realize and commit to their unique role as early interventionists; (2) to enhance workers' confidence, knowledge, and competence to discuss issues such as prevention, testing and treatment with vulnerable young people; and (3) to encourage the development of referral pathways between these services and specialist services e.g. needle exchange, testing and treatment services.

Scotland: Hepatitis C teaching guidance and educational support
A series of toolkits to raise awareness of hepatitis C among young people is provided through an online resource for professionals across Scotland. Lead organizations from health and education have designed the materials for use in three distinct settings: secondary schools, further education colleges and specialist settings that support vulnerable young people.

The content and recommended delivery style of each toolkit has been designed to meet the specific needs of the young people in each setting. Within schools and colleges, the toolkits are incorporated into health and wellbeing curriculums; embedding awareness of hepatitis C into mainstream education in this way ensures that significant numbers of young people have the opportunity to gain essential knowledge about the virus.

Resources for specialist services for vulnerable young people target a sub-population more prone to risk of behaviors such as IDU. The materials and approaches are therefore designed to reflect the range of specific risks they may encounter as well as to convey the basic awareness messages appropriate for all young people.

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Key Message 5:

"Maximize post-diagnosis care"

Following a positive hepatitis C test it is important that patients are offered all necessary support, as well as further assessment and, when appropriate, antiviral treatment.

Patients' needs and preferences must be central to decisions and each individual must be supported to make informed choices. Hepatitis C treatment often won't begin immediately after diagnosis, and some people will choose not to have treatment at all, but much can be done to maintain and improve health irrespective of treatment access and choices. Advice on management of the illness as well as lifestyle changes such as addressing drug or alcohol addiction or improving diet must be accessible to all diagnosed.

In addition, special treatment needs, co-infections or other co-morbidities, potential stigmatization and exclusion from medical systems and society are all stark realities for injecting drug users with hepatitis C. Interventions designed to address just one of these realities will often not meet patients' needs and a collaborative, interdisciplinary approach will be necessary.

Guiding principles for maximizing post-diagnosis care:

1. Antiviral treatment is not always necessary here and now. Hepatitis C does, however, need to be monitored and the decisions relating to whether or when to treat have to be considered on an ongoing basis, including where drug use is ongoing.
2. A multidisciplinary approach or a "Managed Care Network" (MCN), which includes comprehensive screening, treatment, counseling and links to tertiary support, is needed (see also Key Message 11, "Work Together!") to enhance adherence to treatment and care.
3. Information should be peer based and setting based.
4. The principles of adherence are fundamental to management and treatment of hepatitis C: the physician should understand, and respect, the patient's individual preferences and needs, including if there is continued drug use. Patient and doctor should work together for effective disease management and care.

Key components of post-diagnosis care:

Setting approach: Consultation, screening, treatment and care are embedded in a network of different professions and partners. Both health and social services are involved.

Needs assessment: The needs of the target group and capacity of stakeholders and organizations involved to meet the needs are evaluated. This includes assessment of performance, challenges and gaps in existing provision.

Evaluation: Clinical and epidemiological data and risk factor information support the development of interventions. Where appropriate this is tailored to specific target groups. All data are monitored to support and improve service provision.

In practice:

Manchester, UK: Specialist qualifications for hepatitis C nurses

The UK National Institute for Health and Clinical Excellence recommends a clinical nurse specialist should be involved in assessing and treating all hepatitis C patients. In response to this guidance, and coupled with their own experience, the association of Greater Manchester Primary Care Trusts developed standards and recommendations for qualifying nurses in this area (1).

Specialized nurses focus on people or groups who are hard to reach or who need additional support to manage treatment and care. Their work is community-based and includes outreach and cooperation with drug agencies. They also provide training to other staff to improve wider knowledge and understanding of hepatitis C.

Nursing associations in Canada and Australia and other parts of the UK have also developed guidelines and standards to expand the role of registered nurses, nurse practitioners and clinical nurse specialists in integrated concepts of hepatitis C treatment and care (2, 3, 4)

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Key Message 6:

"Low threshold testing increases diagnoses and awareness"

Rates of testing and diagnosis for hepatitis C are low almost everywhere; the majority of people who have hepatitis C globally are undiagnosed.

Testing is necessary to determine whether someone has been exposed to the virus and whether they have chronic hepatitis C.

Early testing can prevent transmission and improve treatment effectiveness and quality of life.

Low threshold access means testing in the simplest form. It's offered outside traditional health care structures and promotes participation of groups who might not be tested in mainstream settings. Low threshold testing is essential to improve both quality of life and to address a potentially significant health and economic burden for society.

Guiding principles for low-threshold interventions:

1. Testing should be voluntary, confidential if desired, accompanied by discussion about the test and implications of being tested and provided with informed consent. Results should be given alongside a comprehensive post test discussion (1).
2. A test must always be the individual's decision, taken using good and relevant information and with professional advice and support.
3. Testing for antibodies and virus should be offered: where possible, different types of test are offered to allow the patient's maximum choice.
4. Testing should be accessible to all those at risk of hepatitis C. Barriers to accessibility such as transportation, language, anonymity or confidentiality, cost, lack of health insurance and/or stigma must be addressed as far as possible.

Key components of low-threshold interventions:

Low barrier method: Marginalized groups are not excluded from mainstream healthcare services, including testing. Access to testing and relevant discussions is easy, provided at appropriate times in an accessible language and location. Counseling and/or testing should be free or affordable for the target group and do not form a barrier to uptake.

Empowerment of target group: Discussions should empower the target group before and after testing. They can assess their risk for hepatitis C and integrate adequate prevention strategies in their daily routine.

Collaborative capacity building / partnership: A network of doctors, medical institutions, public health departments and social workers is consistently available to implement integrated care networks. For marginalized groups links must be created with all relevant partners. Regular staff training and ongoing information exchange should be established across the network; in an existing network, people have faster and better access to the treatment and therapy they need.

In practice:

Germany: community testing and awareness for men who have sex with men
'IWWIT' (Ich weiß, was ich tue; I know what I am doing) HIV testing weeks are part of a national community-based campaign for men who have sex with men. In more than 60 German cities testing is offered by outreach services in a range of settings from traditional clinics to discreet areas in saunas, parties and bars. It can be accessed anonymously and is paid for only by people who can afford it.

The project is coordinated by the Deutsche AIDS-Hilfe, an umbrella organization of German NGOs working in the field of HIV/AIDS. They facilitate information exchange and manage training and quality standards. Building on the successes achieved with HIV testing, some venues now also offer testing for syphilis, hepatitis A, B, and C, gonorrhea and chlamydia.

Germany: low threshold testing and awareness for drug users
Aidshilfe Dortmund's 'Test It' project began as a pilot in 2010. It aims to offer drug users low threshold access to rapid HIV testing in a close contact situation, including drug consumption facilities. HIV testing is provided alongside counseling and awareness-raising for people currently using drugs. The development of individual risk management strategies is also supported.

Based on the successes of the pilot, experience and knowledge gained have been transferred to other projects and will be further developed across the national network of drug consumption rooms. Rapid hepatitis C testing was also introduced in this setting in 2011.

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Key message 7:

"Distributing injecting equipment reduces hepatitis C transmission"

The regular distribution and exchange or disposal of drug consumption equipment reduces the risk of re-use, of sharing and of leaving used objects in places where they may pose a danger to others. It is therefore an essential component of efforts to combat transmission of blood borne viruses through reducing high risk practices.

Distribution and exchange also provides an opportunity for services to engage with injecting drug users on other platforms, and can be used to deliver blood borne virus awareness and testing interventions as well as to promote engagement with general health services.

Guiding principles for equipment distribution interventions:

1. Access to all equipment used to consume drugs is as important as access to needles and syringes.
2. Safe disposal of equipment is vital: disposal should be offered and information provided to ensure drug users are fully aware of how this can be done. Staff should be trained in safety and post exposure procedures.
3. Staff must maintain a pragmatic attitude and respect for the choice of using drugs, without judgment.
4. The guarantee of confidentiality and anonymity is essential.
5. Provision of information on safe consumption practices and of lower risk and alternatives to injecting is an important component of needle and syringe programs.

Key components of effective equipment distribution programs:

Empowerment of the target group: The distribution of drug paraphernalia can promote health and safer consumption (1). Drug users should have access to detailed information about the proper use, maintenance and disposal of injecting or smoking equipment. Knowledge of the risks of hepatitis C transmission and of prevention strategies are essential to empowering drug users to make informed decisions.

Participation and commitment of the target group: All equipment and information provided should be appropriate to target drug users. It is therefore important that they are involved in needs assessments and in service implementation and evaluation. The equipment, components of kits and approaches to their distribution

should reflect the real needs of individuals and facilitate safer consumption practices according to the local situation.

Needs assessment: Paraphernalia should be provided according to the type of consumption, habits and preferences of the target populations. Among drug users, hepatitis C mainly affects those who have injected. However, it is important to provide equipment for other forms of consumption (smoking and snorting for example) as an alternative to injecting. These materials should be easily accessible through distribution and/or exchange points.

In practice:

Netherlands: Improving access to injecting equipment

Needle and syringe distribution facilities are available in all major Dutch cities. Most facilities are operated by staff in institutes for addiction care, in low threshold facilities such as consumption rooms or by outreach workers. Organizations as well as drug users themselves can order injecting and related equipment online at the 'Safe Shop', which operates in co-operation with pharmacy and is run by Dutch NGO Mainline. They supply materials and information for safe injecting, for snorting drugs and for safe sex.

Portugal: Promoting safe alternatives to injecting

Portugal has put into practice the distribution of foil for people who smoke heroin, an approach pioneered by the NGO APDES (Agência Piaget para o Desenvolvimento; Piaget Development Agency). The strategy arose from a needs assessment through which drug users asserted the importance of material targeted at smokers.

Although Portuguese legislation at that time did not permit such services, APDES was able to obtain a permit for their work. The main purpose of the program is to obtain free aluminum foil as a safer alternative to injecting and to avoid the sharing of any equipment. Outreach workers provide information about its safe use with particular emphasis on the importance of individual use of pipes and the risks associated with sharing.

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Key message 8:

"Health education saves lives"

For people unable or unwilling to stop injecting drugs, adopting safer injecting practices is central to improving health, both in the short and long term. Even very basic educational support can enable a much safer approach and a better understanding of the risks.

The goal here is not to transform the person into the perfect injector but instead to work together to identify gradual steps to reduce risks. As injecting practices are often shared within communities, beneficiaries of these training sessions can also play a role as supporter of safer injecting practices among their peers.

Community-based consultations have shown that people who use harm-reduction centers would welcome educational support on how to inject more safely, but that they often do not know where to access reliable advice on this (1, 2). Both the opportunity and the need for this clearly exist across Europe, but are often missed or under-utilized; certainly a few printed leaflets are not enough!

Guiding principles for health education interventions:

1. Educational interventions for injecting drug users need to be based on humanist principles, recognizing that people who use drugs are willing and able to adapt injecting practices to protect their own health.
2. Interventions should be in line with the principles of health promotion and empowerment as defined in the Ottawa charter (3), most notably they take into account - in a non-judgmental way - the capacities and motivations of people who use drugs.
3. Work needs to be multi-sectoral and multi-faceted. This includes efforts to improve (early) access to quality health care and to hepatitis C testing and treatment.
4. Laws that further marginalize people who use drugs should be reformed to effectively tackle hepatitis C and other health risks.
5. Effective educational interventions have been found to involve a number of key features. They should be specifically tailored to the target audience; use appropriate language and (minimal) literacy; allow people to learn at their own pace and practice new behaviors in a safe environment; and are regularly and interactively delivered by people with credibility among the target group (4).

Key components of effective health education interventions:

Needs assessment: People who use drugs often learn to inject from peers and do not know where to access information on safer injecting. Addressing this 'vicious circle' is central to effective health protection and promotion.

Empowerment of the target group: Great care must be taken to ensure training respects and supports the autonomy of people who use drugs. This includes providing a non-judgmental, safe space where questions can be asked and taking the perspective and ideas of people who use drugs into account.

Evaluation: The effectiveness of education on safer injection can be assessed in several ways. Demand for the service, changes in usage, feedback from service users and many other mechanisms will reveal a lot. People should be encouraged to comment freely about their experiences, and this information used to improve the service.

In practice:

France: Training and support in injecting-related health

The French NGOs AIDES and Medecins du Monde have developed specific protocols to provide peer support and training on injection-related risks for people who inject drugs. This involves educational sessions with people seeking to improve their injecting practices and provides both educational exchanges, discussing any injecting-related questions, and self-injection in the presence of trained staff or volunteers to enable direct feedback.

The main objective of these educational sessions is to enable the individual to learn to inject more safely in order to better manage the associated risks.

Australia: Helping people assess their own injecting

Video recording can be a very strong tool in facilitating training in safer injection. Staff at the Sydney Medically Supervised Injecting Center used this approach to maximize the impact and illustrate the relevance of harm reduction messages to each individual drug user.

Watching these videos with trained staff proved especially useful in initiating precise and detailed discussion on injecting practice and strategies to make this safer. A collaborative process, discussions are approached in a way that ensures both an improved understanding of injecting risks, and the responsibility for addressing these, are focused on the person injecting and not any external service or service provider.

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Key message 9:

“Use the expertise of affected communities”

People living with, or at risk of, hepatitis C have essential, practical knowledge of all the issues involved. This must be used to develop effective prevention and treatment programs and strategies for hepatitis C.

Top-down health programs that are based only on the views of traditional experts, such as medical and public health professionals, often achieve limited results because they do not meet the actual needs of the people for whom these programs were designed.

People who use drugs are, as a community, severely impacted by hepatitis C. They need to be fully integrated at all levels: in the work of government, NGOs and the wider community involved with hepatitis C interventions and services.

Guiding principles for community engagement:

1. A central component of enabling drug users is health promotion, defined in the Ottawa charter as: *the process of enabling people to increase control over, and to improve, their health... through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities - their ownership and control of their own endeavors and destinies.*" (1)
2. People living with hepatitis C, and especially those most at risk, need concrete opportunities to meet, exchange and to contribute to the organization of prevention, diagnosis, treatment and care.
3. Hepatitis C programs should specifically support the self-organization of people living with or at risk of hepatitis C, as well as enabling the participation of specialists, healthcare workers and other professionals.

Key components of effective community engagement:

Participation and commitment of the target group: All affected are able to participate in the design, implementation and evaluation of the service, policy or approach. Services use, and are strengthened by, the knowledge and capabilities of affected communities.

Collaborative capacity building / participation: The objectives, methods and activities take into account health inequalities. Prisoners and homeless people, for example, should be able to participate.

Empowerment of the target group: People affected by hepatitis C and people who use drugs are considered integral to the response to it. Additional efforts are made to engage people typically marginalized and who may not, for example, be used to sharing their opinions or working in a 'meeting' environment.

In practice:

France: consultation with all affected to set national priorities

In 2010, French NGOs AIDES and SOS Hepatites jointly organized a community-based national consultation on the needs of people living with hepatitis C. First through local consultations involving 500 people, then through a national meeting with over 100 delegates, people living with hepatitis C were invited to individually and collectively formulate their own assessments of the situation today and changes that need to be made.

The organizers went to lengths to ensure the settings were as favorable as possible for the safe expression of individual needs and aspirations and were as inclusive as possible, for example through securing day release permits for prisoners to attend.

Key recommendations from the group included a need for improved coordination across health and social services and in particular that co-infection with HIV must be considered a specific health condition requiring integrated care. Universal access to prevention, care and support was also identified as a key priority, especially through tailored programs for the most vulnerable. Participants' experience was very positive, and many recorded additional benefits from being involved such as having improved social relationships and developed new skills.

International: a global advocacy network for drug users

The International Network of People who Use Drugs (INPUD) is a *global peer-based organization that seeks to promote the health and defend the rights of people who use drugs* (2). It is a network of people who use drugs, and have used drugs, representing their collective voice to international institutions and national governments.

INPUD campaigns for increased international services to address transmission of hepatitis C and other BBVs, for universal recognition of the human right to health, as well as for legal reform and greater rights for drug users.

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Key Message 10:

"Make hepatitis C services available in prisons"

Across Europe, as well as globally, above average rates of hepatitis C, hepatitis B and HIV are seen in prison populations. This has been attributed to higher levels of injecting drug use, tattooing and unsafe sexual activity occurring both in prisons and among individuals more likely to have spend time in prison (1, 2).

Due to the high proportion of drug users in prisons, these settings provide both the opportunity and the need to deliver awareness, prevention, treatment and care.

As part of the human rights of prisoners, free access to health care, equivalent to that available to the general population, should be accessible, including preventive and public health measures (1).

There is evidence that treatment in prisons is both feasible and improves safety for inmates and staff. Research also suggests that addressing hepatitis C prevalence among prison populations has the potential to reduce prevalence in the general population (3).

Guiding principles for prison-based hepatitis C interventions:

1. Guidelines, protocols and training around hepatitis C and drug use, developed according to government and community sector recommendations, should be available to prison staff.
2. Voluntary hepatitis C testing, including comprehensive pre- and post-test discussions, should be offered alongside monitoring of prisoners' general health.
3. Treatment and care equivalent to, and linked with, that in the local community should be provided, whenever possible inside the prison. This needs embedding in other harm reduction services and should follow the patient if he is moved or released from prison.
4. People in prison with personal experience of hepatitis C and/or drug use should be pro-actively involved with the design and implementation of all related services.
5. Complementary services, such as those to support mental health and sexual health, should be available in the prison alongside, and linked with, hepatitis C services.

Key components of prison-based hepatitis C interventions:

Setting approach: The interventions refer clearly to the structural conditions of prison settings, targeting prison staff and taking into account the limitations and opportunities of this particular context.

Proportionality: The interventions regarding hepatitis C treatment in prison have to take into account a balanced approach regarding the available resources, timing and the scale of the programs to ensure the full coverage of the particular prison population.

Sustainability: The services delivered become general routine in prison settings, which ensures the sustainability of the intervention.

In practice:

Catalonia: Comprehensive hepatitis C prevention in prisons

The hepatitis C strategy in Catalonian prisons includes many diverse, and in many instances groundbreaking, prevention measures.

Methadone maintenance and needle and syringe exchange programs are provided in all prisons in the region. All prisoners are also offered hepatitis A and B vaccination as well as an initial assessment of the likely risks they face in relation to hepatitis and other blood-borne viruses. Education programs for prisoners cover the safe consumption of drugs (such as hygiene measures), the correct handling of drug use equipment, and the risks of sharing equipment and front- and back-loading syringes.

Hepatitis C testing is also offered on site and written information on testing and treatment is available to prisoners. A coordinated network, including liver specialists, has been established to manage the care and treatment of those diagnosed with hepatitis C.

Scotland: bringing national health services into prisons

Since 2008 the Scottish Prisons Service has been working with the Scottish National Health Service (NHS) in their aim to promote the treatment of hepatitis C to all patients in Scotland. The lack of on-site hepatitis C services was identified as a key barrier to prisoners' accessing testing, diagnosis, treatment and care.

To address this they brought relevant NHS services into the prisons, with local NHS systems providing tailored support to ensure new services build on existing provision for prisoners. Today specialist hepatitis C services are available in all Scottish prisons, most testing and diagnoses are now made on site and treatment rates increased more than six-fold in two years (4).

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Key Message 11:

"Work together"

A multidisciplinary approach is necessary to address the complex range of needs often faced by people who have hepatitis C. This is especially important for effective prevention, diagnosis, treatment and care services for IDUs as they often face one or more co-infections as well as addiction and other mental and physical health needs.

A multidisciplinary model of care includes comprehensive screening and treatment for hepatitis C infection, counseling and treatment with regard to substance misuse, opioid substitution therapy, psychiatric services, patient support groups and links to tertiary support. Emerging evidence suggests that such an integrated approach is likely to improve the adherence of drug users to the hepatitis C treatment process (1).

Guiding principles for multidisciplinary hepatitis C interventions:

1. The potential mental, psychological and social challenges faced by the patient must be recognized and understood
2. A pro-active approach should be taken to the patient's drug use
3. Communication should be non-judgmental, taking into account the possibly marginalized position of the patient in society
4. The importance of the patient's contribution through, for example, peer education and highlighting patient rights should be at the center of any approach
5. Training and information provision for staff needs to be provided on an ongoing basis, including through regular exchange and collaboration
6. The importance of privacy and confidentiality must be recognized

Key components of multidisciplinary hepatitis C interventions:

Collaborative capacity building / partnership: Interventions should work with different professions and include cooperation between professionals in a way that helps build skills, capacity and understanding for all parties.

Evaluation: Interventions need to make use of concepts and tools for documentation and evaluation of their own work. Evidence and materials produced (including on the interventions' design, aims and working methods) are accessible to parties who might benefit from them.

Proportionality: Interventions delivered by multidisciplinary teams and agencies have a balance in resources, timing, scale and cost-benefits.

In practice:

Switzerland: Single access points for multidisciplinary services

Based in Zurich, ARUD (Arbeitsgemeinschaft für risikoarmen Umgang mit Drogen; The Association for Risk Reduction in the Use of Drugs) provides a comprehensive range of services for their 1,000 patients in four outpatient centers. The centre offers testing for blood-borne viruses, complete antiviral care for hepatitis C, opioid substitution, psychiatric care, social work and follow-up treatment as well as referral to additional services if required.

As a result, a third of patients diagnosed with chronic hepatitis C have received treatment and completion rates are over 60%. A key success of the approach is enabling patients to access additional care at the same time as substitution therapy and hepatitis C treatment. Strong relationships built between staff and patients, as well as the close links with additional services, provide the comprehensive care and support needed to effectively address hepatitis C and injecting drug use.

Slovenia: National healthcare management network

In Slovenia, a national healthcare network for the complex management of drug users with hepatitis C was established in 2007 by combining drug addiction and viral hepatitis centers.

The network consists of addiction therapists, viral hepatitis specialists, psychiatrists and counselors. There is also a peer-led team who support patients either personally or online as well as other support systems consisting mainly of family members, friends and co-workers. The professional team receive specialist medical as well as supportive education, and hold a national interdisciplinary conference once a year.

According to nationwide monitoring, the proportion of drug users included in hepatitis C treatment regimens has increased from 5% in 1997-1999 to as much as 66% in recent years. In the most recent completed study, in which over a third of drug users participated, only 7% of all treated patients discontinued the treatment due to non-compliance; for treatment naive patients, rates of sustained virological response (SVR) are in line with the results of international clinical trials.

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Key Message 12:

"We need a national action plan!"

A framework or action plan provides an effective and coordinated response from all levels of government, the community, voluntary organizations, the health sector, scientific and research communities and people affected by hepatitis C.

Effective action plans are developed with all stakeholders working in the area of hepatitis C and are linked with other relevant government policies such as those concerning drug use and public health.

Guiding principles for the development of a national action plan:

1. It is vital that plans address all aspects of hepatitis C, from awareness and prevention to treatment and care.
2. Plans should promote equality and a rights-based approach to healthcare in order to facilitate access and treatment and to address stigma and discrimination.
3. Plans need to set clear strategic priorities such as focusing on priority populations, targeted prevention programs, raising awareness among medical staff, improving testing and treatment access.
4. To ensure effective implementation of the plan, clear goals and timelines must be set. Effective surveillance and research is essential to understanding need and evaluating impact.
5. Plans should provide a framework through which services are developed in a multidisciplinary, integrated way. It must be linked to other action plans at local, national and international levels.
6. The action plan cannot be effective without identifying and securing the necessary funds with which it can be implemented and sustained.

Key components of an effective national action plans for hepatitis C:

Needs assessment: The extent and nature of needs across the general population as well as for specific, more affected groups, has been comprehensively evaluated.

Priorities, aims and objectives have been set based on available evidence. An implementation plan has been developed and monitoring and evaluation systems are in place to ensure this is carried out effectively and to inform future work.

Collaborative capacity building / partnership: Partnership working occurs at all levels and across all relevant disciplines. People affected by hepatitis C, service users and patients are involved.

The action plan and agreed priorities are produced through a collaborative process involving all relevant parties. It provides a robust framework which facilitates collaboration and ensures that the activity of all relevant sectors is coordinated and complementary.

Sustainability: The action plan takes a long-term strategic approach. The prevention, diagnosis and treatment of hepatitis C is approached as an integral part of public health and health care.

All activities carried out under the action plan are regularly evaluated. Evidence-based strategies and actions are used to continuously improve services and maintain their relevance to the changing needs of affected populations.

In practice:

Australia: Ground breaking beginners with a long-term approach

Australia was the first country in the world to develop a national hepatitis C strategy.

In 1994 the government published its first position paper on hepatitis C and, following extensive consultation, the first Australian National Hepatitis C Strategy was introduced in 1999. Over the following 12 years 2 further time-bound strategies have been developed, responding to changing context, knowledge and need in the population.

The National Hepatitis C Strategy is one of five national strategies to cope with sexually transmitted infections and blood-borne viruses in Australia.

Over the years since the first strategy was implemented Australia has seen substantial reductions in hepatitis C. The number of new diagnoses declined from approximately 20,000 in the year 2000 to 11,500 in 2009. Estimated incidence reflects this drop, having almost halved from 105.2 to 51.9 per 100,000 population in the same period (1).

Scotland: Evidence-based action plan for hepatitis C

Scotland's hepatitis C action plans began with a single consensus agreement from leading practitioners in the field recognizing the urgent need for a coordinated, strategic approach to address hepatitis C.

Scotland's plans have been developed in two phases. The first (2006 – 2008) established governance and oversight, educated practitioners, gathered evidence on epidemiology and need. This evidence was used to develop specific recommendations, clearly identified outcomes and the actions required to achieve

them under three overarching aims: preventing transmissions, especially among IDUs, increasing rates of diagnosis and ensuring people who have hepatitis C have access to optimal treatment, care and support (2).

The second phase (2008 – 2011), supported with almost €49 million in funding, implemented these recommendations over three years. The plans were developed collaboratively and set to clear and measurable timelines and goals.

From 2007 to 2009 Scotland saw a 34% increase in diagnoses, while the number of people accessing treatment has doubled (2, 3). Through procuring antiviral drugs at a national level an average 20% reduction in costs has also been achieved (2).

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