MANIFESTO

Hepatitis C:
Access to Prevention, Testing, Treatment and Care for People who Use Drugs

Hepatitis C is a Major Global Public Health Problem!

THE TIME TO ACT IS NOW!

HEPATITIS C STATISTICS AND POLICY FACTS:

- 150 million people worldwide are living with chronic hepatitis C virus (HCV), of those infected, nine million are living in the European region [1,2].
- The burden of HCV is concentrated among people who inject drugs (PWID) in Europe, with HCV antibody prevalence ranging from 20% to over 90% in different countries [3]. The World Health Organization (WHO) has identified people who inject drugs as a key target group for HCV prevention and treatment [4].
- In January 2014, the first all oral HCV treatments providing cure rates of up to 98% in clinical trials were approved by the European Commission [5].
- In spite of European guidelines recommending treatment access [15] people who use drugs still face considerable barriers to, and are frequently denied, access to the newly approved HCV treatment regimens [6].
- The scale-up of HCV treatment access to people who inject drugs has the potential to significantly reduce the number of new infections and the prevalence in the population, acting as an effective preventative measure [7].

Major European and international agencies working in, or involved with health and drugs, such as WHO, UNODC, UNAIDS, EMCDDA and ECDC consider viral hepatitis, especially among people who inject drugs, a serious public health problem.

At present polices responding to HCV are inconsistent, or non-existent across Europe [8]. The broad range of issues pertaining to HCV have not been thoroughly included in European and/or national policies, or comprehensively dealt with among designated stakeholders. HCV prevention, screening, early diagnosis, and treatment among people who inject drugs have been proven to be both effective and cost effective [9].

Research exploring the values and preferences of people who inject drugs with regards to HCV treatment has found that concerns about side effects; limited HCV knowledge; rationed treatment expectations; experiences of treatment refusal due to drug use; stigma and discrimination within healthcare settings; and difficulties associated with hospital systems pose significant hurdles for HCV treatment, access and uptake [10].

Presently, public awareness, surveillance systems, availability of HCV prevention and harm reduction based interventions remain inconsistent throughout Europe. Access to screening and diagnosis services are not available to people who use drugs in every country. Importantly there has been little attention to addressing the stigma and discrimination faced by people who use drugs and even higher among people who inject; this is a major barrier to accessing services and requires urgent remedial action if effective HCV policy and programming is to be implemented [11]. The time to foster a unified global response to the hepatitis C epidemic is now!

THE TIME TO ACT IS NOW!

- **Develop Targeted HCV Strategies and Action Plans**

We strongly recommend the development and implementation of European and national HCV strategies and action plans that include appropriate funded multidisciplinary approaches for HCV prevention and control among communities engaged in high-risk behaviours including people who inject drugs, in line with the 2014 WHO resolution WHA67.6 OP1(1) [12].

Action Required: Policy-makers, NGOs/service providers, representatives from at high-risk populations, such as organisations of people who use drugs, and workers in the health care, social and justice sectors, must collaborate (at European and national levels) for the development of comprehensive HCV strategic plans and service recommendations. Public funding must be allocated for the development, implementation and evaluation of effective HCV strategic planning and services [13].

The evidence: (1) The Global Commission on Drug Policy commends that "Governments must immediately redirect resources away from the 'war on drugs' and into public health approaches that maximise hepatitis C prevention and care, developed with the involvement of, the most affected communities" (p. 3) [14]. (2) A follow-up of the WHA Resolution 63/18 on viral hepatitis, Sixty-fifth World Health Assembly (WHO, 2012d) Session and Progress Report, states that "in order to respond to the requests made in the resolution, the Secretariat is taking a broad approach, including scaling up successful interventions, strengthening health systems and developing new approaches, at the same time mobilizing much-needed resources" (p.17) [15].

Provide Access to HCV Testing, Treatment and Care Services

We strongly recommend the provision of low threshold and community based HCV testing (voluntary, confidential and free of charge) and referral to affordable and high quality treatment (interferon free) and care for HCV. Provision of HCV testing and treatment uptake among PUD in low threshold settings has been proven to be effective and cost-effective [16]. Despite issues of limited access, newly approved HCV treatments, direct acting anti-virals (DAAs), have shown to be effective and well adhered among people who use drugs in recent studies [6].

Action required: Implementation of comprehensive national policies to fund and support integrated and accessible programs for HCV testing and treatment, offered in non-traditional and low threshold community-based settings [17]. Consensus agreements must be made among pharmaceutical companies and EU member

states to reduce prices of new medications to allow the scale-up of treatment, thereby allowing for equitable access to affordable treatments.

The evidence: (1) Hagan and Schinazi (2012) report that "Hepatitis C virus treatment options have evolved rapidly. (…) Cure rates, measured by sustained virologic response (SVR), have increased from just 10% among patients treated with interferon monotherapy in 1990 to 80% in some genotypes with current standard of care. (…) once successful vaccines have been developed, local health departments can partner with pharmaceutical companies, clinicians, media organizations and advocacy groups to implement vaccination campaigns with both prophylactic and therapeutic value" (p. 70) [18]. (2) The Health Consumer Powerhouse (2012) states that "high quality, accessible care (possibly in non traditional settings, *i.e.* outside clinics or hospitals) should be provided to improve results and adherence to treatment" (p. 13) [19].

- **Scale-up Harm Reduction, evidence and Community-Based Programs**

We strongly recommend the scale-up of harm reduction, NPS and community-based programs ensuring high quality, effective and sustainable coverage. Research has shown that a combination of integrated interventions in low threshold settings such as NSPs, opioid substitution therapy (OST), access to medicalised heroin and community based, peer led harm reduction programs are not only cost effective regarding HCV prevention, but also ensure that marginalised populations stay connected to direly needed services [20].

Action required: Implementation of comprehensive integrated harm reduction based HCV prevention services, involving members of the most affected community, that include evidence based interventions such as OST in low threshold settings. The establishment of policies that ensure appropriate financial resources are made available for capacity building, and the empowerment of organisations of people who inject drugs, and provision of prevention interventions recommended by WHO.

The evidence: (1) "Directly observed HCV treatment programmes that are integrated with substance abuse treatment, education, peer support and linkage to tertiary care have shown the greatest success among IDU (Litwin AH, Soloway I, Gourevitch MN, 2005 cit. in Hagan and Schinazi, 2013, p. 73) [18]. (2) "Harm reduction services – such as the provision of sterile needles and syringes and opioid substitution therapy – can effectively prevent hepatitis C transmission among people who inject drugs, provided they are accessible and delivered at the required scale." (Global Commission on Drug Policy, 2013, p. 3) [14]. (3) The EU action plan 2009-2012 (Council of the European Union, 2008) recommends the "access to harm reduction services, in order to reduce the spread of hepatitis C" (p.14) [21]. (4) The EU action plan 2005-2008 (Council of the European Union, 2005) includes the "prevention of the spread of hepatitis C ensuring the implementation of comprehensive and coordinated national and/or regional programmes on hepatitis C integrated into general social and health care services" (p.7) [22].

- **Decriminalize People Who Use Drugs**

We strongly recommend all EU member states to adopt laws that decriminalize people who use drugs and prosecute human rights violations that threaten access to, or deny, essential life saving services, such as NSP, harm reduction and treatment services. In many countries, members of law enforcement have been responsible for confiscating drug injection supplies and sterile syringes intended to prevent the transmission of HCV and HIV. Numerous studies show that such actions are responsible for increasing injection risk behaviours and countless numbers of entirely preventable HCV infections [23].

Action required: Drug policies and laws that criminalize possession of drugs must be reformed or removed to stop the marginalization of people who use drugs and to guarantee free access to essential health services, including harm reduction, namely NSP, HCV/HIV prevention and treatment programs. National governments should adopt new drug policies based on a human rights approach fighting against the stigma

and discrimination that denies access to HCV treatment to people who use drugs or who are on opiate substitution therapy (OST).

The evidence: (1) The Global Commission on Drug Policy (2013) point that the decriminalization of people who use drugs and the refuse of stigma and discrimination, redirecting resources to public health approaches, can capitalize hepatitis C prevention and control [14]. (2) Wolfe, Carrieri, & Shepard (2010) note that criminalization laws "perpetuate unsafe injection practices and drive people underground and away from essential health services" (Wolfe, Carrieri, & Shepard, 2010 *cit. in* Clayden, et al., 2013, p. 44) [24]. (3) Several International organisations such as UNHCR, UNAIDS and WHO recommend that "Legislators and other government authorities should establish and enforce antidiscrimination and protective laws in order to eliminate stigma, discrimination and violence faced by PWID and to reduce their vulnerability to infection with viral hepatitis" (UNHCR & UNAIDS, 2006 *cit. in* WHO, 2012b, p. 18) [25].

- **Meaningful inclusion of People who Inject Drugs and their organisations**

We strongly recommend meaningful involvement of communities living with the highest risk of HCV, namely people who use or have used drugs, in all levels of HCV policy development, including the development and provision of harm reduction, HCV prevention, treatment and care services. The involvement of most affected communities is critically important for the development of successful and effective policies and services. Peer based HCV prevention programs and interventions have been proven most effective in reducing transmission of viral hepatitis and HIV [26, 27].

Action Required: European policies and member states policies must include mandates that require the involvement and representation of high-risk communities in decision-making processes related to HCV policies and services. EU and national support must be provided to ensure implementation and sustainability of peer-led HCV services, and consequently must fund drug user led organisations to provide peer to peer education, and low threshold harm reduction services.

The evidence: (1) The WHO Guidance on Prevention of Viral Hepatitis B and C Among People who Inject Drugs recommends peer based, or peer led interventions, noting that "in contrast to other psychosocial interventions, delivered by health workers, evidence showed that interventions delivered by peers were effective in reducing transmission of viral hepatitis"(p.9) [25]. (2) Governments should "establishing national hepatitis C strategies and action plans with the input of civil society, affected communities, and actors from across the HIV, public health, social policy, drug control and criminal justice sectors" (Global Commission on Drug Policy, 2013, p. 3) [14]. (3) Meaningfully involve the civil society, affected communities, including people who use drugs, and other relevant stakeholders from various fields. Auscultation and hearing process should be included in process of developing HCV Policies, in order to promote a "consensus building and mutually respected objectives", by actors of all sectors, as this is "essential when it comes to the successful implementation of interventions" (ECDC & EMCDDA, 2011) [28].

- **Increase Health and HCV Literacy**

We strongly recommend the development and implementation of standardized training for healthcare workers and for people who use drugs on HCV prevention, treatment updates and drug use issues. Evidence suggests that healthcare workers and people who inject drugs often lack sufficient health literacy on hepatitis, which negatively influences decisions regarding appropriate prevention and treatment options [29, 30].

Action Required: The development and implementation of EU and nationally supported training programs on HCV and drug use for healthcare workers (including Nurses and GPs) and people who use or inject drugs. People who inject drugs and their organisations must be at the centre of health and HCV literacy measures. Dedicated funding must be allocated for the development of interventions that will improve the knowledge and skill level regarding HCV treatment and drug use/user cultural issues among healthcare professionals, including specialists such as hepatologists and gastroenterologists. Peer based organisations of people who inject and use drugs must be funded to produce and provide education and training, addressing gaps in knowledge among healthcare workers and peers in regard to cultural and specific needs of people who use drugs to ensure beneficial health outcomes.

The evidence: (1) The World Health Organization (2012) reports that often, PWID's lack of health literacy on viral hepatitis, its prevention, care and treatment options, can block their informed decision-making [25]. (2) "Health services should strengthen providers' knowledge and capacity to prevent and to treat viral hepatitis in PWID" (p. 19) [25]. (3) Low awareness of hepatitis among relevant stakeholders, as policy and decision-makers, has limited the impact of evidence-based strategies for prevention and control of viral hepatitis. "Increasing awareness is also key to making hepatitis a larger part of local, national and regional health agenda" (WHO, 2013, p.1) [31].

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