INPUD Statement at
WHO Global Hepatitis Partners meeting, Geneva,
28th March 2014

WHO Leadership is STILL MISSING

On World Hepatitis Day last year, a group of civil society organisations working primarily on HCV issues launched a campaign called 'MISSING' to draw attention to the fact that the leadership of the WHO has been largely silent on hepatitis issues, we condemned Dr Chan for being MISSING when it comes to giving strong statements on the subject in spite of the massive scale of the epidemic. The fact that her opening message was video broadcast here and not delivered in person has prompted us to update our campaign to STILL MISSING. Whilst we welcome the convening of this important meeting, Dr Chan's presence would have been a vital sign of the seriousness with which she intends to address the ticking "viral time bomb" of viral hepatitis.

As is suggested by the name of the organisation that I represent, one of my primary concerns is with ensuring not just equitable but comprehensive and universal access to hepatitis diagnostics, treatment and care for the injecting community, and it is to that issue that I will address my remarks, most of which can be taken to refer primarily to HCV, and to a lesser degree HBV. Some figures to give you an idea as to the scale of the problem: 10 out of the 16 million injecting drug users worldwide are living with HCV, and the percentage who are currently receiving access to treatment, is a mere fraction of 1%. Up to 90% of new HCV infections occur amongst the injecting community. The way in which the latter fact is usually presented is "injecting drug use" drives HCV, it is not the fact of injecting that is driving the epidemic, but a shameful lack of political will and the subsequent massive underinvestment in needle and syringe programming, which in turn drives the need to share injecting equipment amongst the injecting community.

This lack of access to treatment is structurally driven and goes way beyond price, the fact is that in most countries currently active injecting drug users are either systemically denied treatment or face such significant stigma within healthcare settings that we are all too often afraid to approach them and or are actively discouraged from doing so. We are told that we are not adherent and that treatment is not effective for our community and or that we will only go out and get re-infected. All of this is to devalue our lives and is based on stigma, misinformation, and a failure to meaningfully engage with our community.

Dr Chan in her opening address described those communities most affected by hepatitis as "poor and marginalised", this is true as the vast bulk of the epidemic does indeed fall in low

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and middle income countries, but in the case of the injecting community, the community most heavily and disproportionately affected by HCV, with 10 out of 16 million of us living with the virus, you have to add in the significant barriers to treatment and care created by being systematically discriminated against, and in particular, by being criminalised.

If we want to talk about learning lessons from the HIV movement let me remind you of three - we have to take on a human right agenda, we have, if we are to seriously address HCV begin to talk about systemic drug law reform, and we have to meaningfully involve the most affected communities, and that means my community which is so often misleadingly described as hard to reach.

The scientific consensus statement on harm reduction launched at CND last week made it very clear that the principal driver of HIV and HCV is criminalisation. Whilst the HIV sector has long recognised, at least in word, the social and political drivers of the epidemic, the HCV sector, has, as in so many other respects lagged far behind. It is my concern that this be redressed. It is long overdue that we come to see viral hepatitis, most notably HCV and HBV as epidemics of exclusion, stigma, and criminalisation, notably too we must come to recognise that HCV is a human rights issue.

In spite of the fact that prevalence rates of HCV amongst the injecting community dwarf HIV rates by several orders of magnitude, harm reduction, the most evidence based, human rights compliant set of prevention technologies applicable to the drug using, and specifically, injecting community, has largely been driven by an HIV agenda. That HIV orientated harm reduction has not been sufficient to address HCV is clearly demonstrated by the fact that even in countries such as the UK and Australia that have long had fairly widespread harm reduction programming, most notably NSP, we have managed to keep HIV prevalence rates down to around 1.2%, yet we have HCV prevalence rates at around the 50% mark.

It was only this year with a peer reviewed article demonstrating that the HCV virus remains infective for up to 6 weeks in dried blood spots that something that we have long known in the injecting community became a part of scientific knowledge. This fact alone underlines the urgent truth that setting our harm reduction objectives by HIV is insufficient, and indeed counter-productive.

Clearly, we need to set our targets and our objectives in harm reduction very differently. We in the injecting community have long known that hepatitis is a major issue for us - indeed the harm reduction movement was started by, and comes from, our community.

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The world's first NSP was established by a group of injecting drug users in Rotterdam in the late 1970s in response to what was then known as NANB hepatitis. Our community has never been silent on the issue, and our organisations have been conducting peer education on the subject, for in some countries over 20 years, it's just taken up until now for anyone else to listen.

So if we are serious about addressing HCV we need to invest in and build the capacity of peer based organisations of people who inject drugs and resource us to design and conduct peer education campaigns.

We need to address repressive drug policy and the legal environments that they create which systemically drive human rights abuses, most notably denial of the right to the highest attainable standard of health, which manifests itself most clearly in the failure to invest in comprehensive harm reduction programming and in many settings keeps our community away from accessing health care services for fear of compulsory registries, condemnation to enforced detoxification centres, arrest, abuse, and stigmatisation both within and without healthcare settings.

Finally we need strong clear leadership from WHO on the severity of the public health catastrophe that hepatitis represents and we need a reversal of the lack of political will to address the issues that has left HCV a second thought, barely on the political agenda of most countries. On the ground this will require the meaningful involvement of our communities in not only the creation of national strategic plans, but also in the design, implementation and monitoring of services that are supposed to cater to our needs, backed up by the creation of enabling legal environments that enable us to safely access community based and led prevention services and, as a major priority, a massive ramping up of access to the new treatments to close the frankly offensive treatment gap.

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STILL MISSING

Leadership by WHO Director Dr Margaret Chan

185 MILLION INFECTED

3-4 MILLION NEW INFECTIONS PER YEAR

350,000 DEAD ANNUALLY FROM HCV

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