

Report from INSHU Community day for User-organizations / NGOs, Oslo 6th of September 2016

Background

User-organizations/NGO and community members were gathered in Oslo in conjunction with the INSHU 2016 – 5th international Symposium on Hepatitis Care in Substance Users in Oslo .The delegates met one day before the INHSU Symposium, and the aims of the meeting was as followed:

- Network and develop supportive professional relationships
- Gain an understanding of the global hepatitis C (HCV) treatment landscape
- Learn from each other`s perspectives and the value of our peer to peer projects
- Discuss challenges and strategies for people working in community settings in linking people who use drugs to testing and treatment
- Provide opportunities for community stakeholders to support and mentor each other and to increase benefit from the conference. Create engagement, and take action!

The community day was hosted by the two Norwegian organizations proLAR and RIO. Moreover, the participants came from several countries: Norway, Sweden, Denmark, Greece, Finland, UK, Portugal, Slovenia, Netherlands, Australia, Vietnam, Indonesia, Myanmar and India.



Jason Farrell from Correlation network gave the participants a quick overview of the conference topics

He listed some key elements to be aware of and we had a discussion:

- NGOs have successfully organized user services
- NGOs are not pro-active to train, hire and supervise

- Very few services are provided by peers
- Staff and management are not aware of structured peer inventions
- Many organizations are eager to get on with the work
- Policy and laws prevent testing by non- medicals, but the MSM community has been successful conducting rapid testing.
- WHY don't use drug-users as testers of HCV on other users
– Kind of “health users”



- Community members should present their work at the conference
- We should show examples on how researchers and advocates can work together to change policy or implement services
- We need to increase access to research to help implement effective HEP C prevention – and to educate community members
- We should have more interventions provided by drug- users. We need a prevention plan, to identify risk behavior- and to help users sustain this preventing behavior
- We need to teach those who are drug-users how to talk to/ with drug-users

Delegates from the different countries presented their organization and their work

There was a wide range of projects and advocating. We found that many things were different regarding laws and politics – and thereby the national healthcare system. Furthermore, there were differences in how the healthcare system and the politics included and treasured the community advocates. For example: as there are low threshold needle exchange programs in many countries, and naloxone available for the users, Sweden do not have any of this but a rather extreme law enforcement when it comes to this.

And as Norway has an injection room and a low threshold HEP C clinic which the group visited, the delegates from Myanmar showed us pictures of how their users were shooting up between “mountains of used syringes” and toddlers. Last, but not least, it became clear that Australia is in lead regarding to offer treatment to all HEP C patients, whereas other rich countries still deny to take the HEP C epidemic serious, and keep on offering treatment only to those who get sick enough.



Common issues for the present organizations on the Community day meeting

SERVICES

- Supervision in harm reduction programmes must be improved
- Funding for supplies and HEP C support services is needed
- Knowledge of peer delivered interventions can be upscaled

POLICY

- Money for treatment
- HEP C guide lines in all countries
- More collaboration in providing services
- More delivered services by peers – Community based testing by non-medical people + other “user friendly” points
- Collaboration with researchers , define their priorities not just participate on their terms – The drug-users “bill of rights” when participating in research
- Access to treatment for all –

We all talked about a common statement that we could stand behind, and as all countries have different challenges, we could not make a common demand about our needs. But one thing we do agree for is that “our experience and involvement are hugely valuable and is definitely needed to end this epidemic”

We had a great day, and enjoyed our possibility to get together and be part of the INHSU conference these days 6-9 sept 2016. It also gave us a chance to have meetings at night, so we could strengthen our network.



EuroNPUD meeting at night 😊

Thanks to the INHSU Conference, president Jason Grebely, for facilitated this event.

We want to thank AbbVie Norway, AbbVie Sweden and GILEAD for supporting us with funds to make the most out of these days in Oslo.

Thank you!

Ronny Bjørnstad proLAR and Line Eikenes Langsholt RIO