

European Network of People who Use Drugs Project Final Report

1) Introduction

This project has been the first attempt to effectively map the extent, nature, strengths, weaknesses and overall state of drug user organising across the European region (sub-divided, sometimes, unhelpfully, into North, East, and Southern sub-regions). The data gathered gives us an extremely rich, nuanced picture of the multi-faceted and widely varying nature of the constituent groups who came together in Marseille on 5th October 2011 to participate in the founding meeting of the *European Network of People who Use Drugs* (EuroNPUD), and gives clear indications for the directions that the network should take, the areas of activity that it will focus its energies on, the challenges that it faces, and the opportunities that are open to it. The meeting assessed the current state of the network, taking account of its perceived strengths and weaknesses, and made a preliminary start on mapping out the actions that it will need to take in order to progress, develop and flourish.

The work has been carried out, with the support of a grant from the European Union, in parallel with the development of the *European Harm Reduction Network* (EuroHRN) which was launched at its own founding conference on the days after the EuroNPUD founding meeting. Whilst EuroHRN aims to “reduce the health and social harms related to drugs and the policy environment, by promoting the human rights and health of people who use drugs through collective advocacy, research and information exchange”¹, it has recognized from its inception that the meaningful involvement of people who use drugs is absolutely crucial to its success, and it is for this reason that the development of our network has been seen as an integral part of its capacity building and launch process. This has been a welcome recognition of the fact that when it comes to representing the views of, and designing services and policies for a marginalized, criminalised and oppressed community, in this case people who use drugs, it is that community and its organisations who are the real experts; this is part of a wider recognition within the harm reduction movement that it is no longer possible for the global discussion on drug policy to continue without the full involvement of those most acutely affected i.e. people who use drugs. As such, this dual network building process has been a concrete example of the meaningful participation of people who use drugs in all policies and programmes that concern them. There

¹ www.eurohrn.eu

is every expectation that the two networks will maintain, build and strengthen ties by engaging in joint campaigns, that will both boost capacity and act as conduits for mutual learning and cooperation.

2) Methodology

The methodology used to acquire this data had two major components, which result in two principal outputs. The first data collection exercise led to the creation of a 'Directory of Organisations of People who Use Drugs in Europe'. Having established this as a baseline of the organisations to be targeted for further investigation, we presented those who had asked to be included in the 'Directory' with the second component of the investigation, namely a detailed Questionnaire to be answered by the leaders of the groups who asked to be included in the Directory. This report represents an analysis of the data gathered by the questionnaire with special attention paid to the presentation of an overview of the character, extent, and action repertoire of the groups who responded. Equally it is hoped that lessons will be drawn to guide us on best practice in the furtherance of drug user organising across Europe, and to reveal gaps in coverage. The latter will enable us to concentrate our capacity building efforts in countries where drug user organising is either weak or non-existent.

The invitation to submit an entry to the Directory was sent out to known organisations of people who use drugs (PUDs), and through contacts with known individuals (both activists and harm reduction professionals) in countries where we weren't aware of any organised groups, this latter process led us to come into contact with a number of groups that we weren't previously aware of.

The intertwined histories of the harm reduction movement and that of people who use drugs in Europe is a complex one, but when overlaid on the broader history of the European Union's Eastward expansion over the last two decades since the fall of the Berlin Wall and the collapse of the Soviet satellite states (some of whom were once known as 'accession states') it becomes even more tortuous and takes on new layers of complexity and variety. The clear and mutually beneficial relationships between professional harm reduction organisations and those led by and for people who use drugs are clearly demonstrated in the collected data.

When designing the Directory and deciding on a format, the decision was taken that entries were to be free form and not forced to fit into a template. Respondents were simply sent an email requesting that they send in “contact details of your organisations and a brief, one paragraph description of what you do”. It was also stated that we were “primarily looking for national organisations, but [that] significant local/regional ones will also be included” and it was made clear that the directory would only include “organisations by and for people who use drugs, it will not include professional Harm Reduction organisations, or NGOs that are not led by and for people who use drugs”. The replies that came in were as varied in their formats as they were in their contents. The only constant feature was, as requested, contact details, but even these varied – some submitted phone numbers and addresses, some FaceBook details and website addresses. Some did indeed submit the requested one paragraph; others sent more than a page of detailed, sometimes historically valuable information; other groups sent in manifestoes and extensive information on their goals, strategy and tactics. As a result, the Directory in itself contains a rich amount of descriptive, and some historical, data on the nature, ambitions, action repertoires and tactics deployed by organisations of people who use drugs across Europe.

It is intended that the Directory will be made available online and as such it is open ended and subject to change, to the addition of new groups as they emerge, and also, but hopefully not, of the removal of groups as they dissolve. In other words, it will present a living picture of the state of drug user organising across Europe from this point onwards.

The second stage of the data collection and mapping was the design and dissemination of a detailed Questionnaire designed to be filled out by the leaders of the groups represented in the Directory. This Questionnaire was carefully written to draw out as rich a picture as possible of the organisational structures, histories, financial position, membership breakdowns in terms of age and gender, strengths, weaknesses, threats to, and opportunities of, the organisations that responded.

Combined together the Directory and Questionnaire responses give an extremely detailed picture or snapshot of the current state of drug user organising across Europe. Whilst there is enormous variety in the form and nature of the different groups, there are also clearly identifiable common points and themes, ranging from political orientation, to modes of organisation, tactics, strategies, and future outlooks. The collected data forms in and of itself a solid database of

information upon which to construct a European wide network that accurately represents the imperatives, voices, priorities and desires of organised people who use drugs in Europe. The methodology employed is, I would contend, a solid, reliable and replicable model for network strengthening that can easily be rolled out across other regions in which INPUD is active. The exercise confirms lessons from organisation theory that show that strong, representative international networks, only thrive when based on active grass roots participation at a local level, with knowledge being transmitted upwards across cities, countries, and then regions. This allows for the cascading upwards of lessons from the street to international and regional advocates working in policy and other advocacy fora.

3) Analysis

In total the Directory contains 30 separate entries (approximately 4 of the entries represent National networks which are composed of anything from 4 to 50 local groups). In terms of the sub-regional distribution, 18 entries came from the Northern region (with 4 countries having multiple entries), 5 from the Southern region (here, one of the countries, France, was represented by a national network with 4 local groups), and 7 from the Eastern region. In terms of areas in which drug user organising has been found to be nonexistent we can count 4 countries in the Northern sub-region, 2 countries in the Southern sub-region, and 10 in the Eastern sub-region. Closer analysis of the distribution of groups in the Eastern region shows that the Baltic States are completely devoid of organisations of people who use drugs. The absence of groups in the countries missing from the Eastern sub-region was confirmed by discussion with representatives from the *Eurasian Harm Reduction Network*. Of the 30 groups who feature in the Directory, 14 went on to complete the Questionnaire, and 12 were present at the founding meeting in Marseille.

Given the history of drug user organising in Europe, it was not surprising to find that all of the groups who responded to the Questionnaire are organisations led by and aimed at heroin or opiate users, and/or people enrolled on opiate substitution programmes. The only exception to this are two groups in the Directory, in Belgium and the Czech Republic, which are Cannabis social clubs, neither of these groups however went onto complete the Questionnaire, nor did they participate in the founding meeting of EuroNPUD. That this is the demographic most

strongly organised is clearly shown in the responses to the question, ‘What kind of people who use drugs does your group represent?’:

People who use heroin and other opiates 100.0%

People who use cocaine 78.6%

People who use crack, methamphetamines and amphetamine 71.4%

People who inject drugs 100.0%

People who use cannabis 35.7%

People who use party drugs 50.0%

People who receive prescribed substitutes for their drug of choice 100.0%

In other words, 100% of the groups described themselves as being for people who use heroin and other opiates, for injectors, and for people receiving prescribed opiates as part of a substitution programme. This too was the exact profile of the groups who followed the process all the way through by sending a representative to the founding meeting.

This result might be partly influenced by our recruitment method which drew upon the resources and contacts of both the *International Network of People who Use Drugs* (INPUD) and the harm reduction movement, both of which concentrate their efforts on that section of the drug using community that suffers the greatest human rights abuses, degrees of marginalization, and public health problems (principally in the form of blood borne viruses), namely injecting heroin users, and users of substitution programmes, but is also a reflection of the dominant concerns that have driven the movement for the rights of people who use drugs historically since the emergence of the *Junkiebonds* in the Netherlands in the 1970s. This possible inbuilt bias in the methodology does not however account for the self-selecting out from successive stages of the data gathering and network building process i.e. from Directory inclusion, to Questionnaire completion, to representation at Marseille. The vast bulk of the groups in the Directory, and all of the groups in the latter two stages of the process, are, whether consciously or not, located within the tradition that descends from those historic origins. The focus on injecting drug users naturally leads the groups included in both the Directory and the Questionnaire to concentrate on very similar activities – notably, the provision, often on a peer to peer level of needle exchange and other harm reduction materials and paraphernalia (50% of the groups surveyed listed injecting paraphernalia as being amongst the facilities that they provided), syringe patrols (a technique arguably pioneered by the Danish *BrugerForeningen* (the Danish Drug Users’ Union), but much copied by other groups across the region – 64.3% of groups responded that they

carried out syringe patrol and distribution), and blood borne virus prevention strategies (85.7% of responding organisations provided this). Similarly, the predominance of heroin users amongst the groups represented has also inevitably produced a preoccupation with national opiate substitution programmes, and a very distinct grappling with the implications of adopting, combating or strategically engaging with the subject position of being a patient. The data gathered clearly demonstrates that most of the groups covered maintain a complex, guarded and ambivalent relationship with wholesale adoption of the patient identity, and several actively resisted it, such that, none of the groups who responded to the questionnaire defined themselves primarily as a patient's representative group, many of the groups opted for variants on *Brugerforeningen's* 'active drug user', or the previous subtitle of ASUD's journal, "le journal des drogués heureux" (the magazine for happy drug users).

This complicated relationship is demonstrated by responses to the question "What sort of group are you?" where the responses were as follows:

Patient interest group 57.1%
Activist group 85.7%
 Lobby Group 71.4%
 Service provider 57.1%
 Other 35.7%⁵

There is clearly some overlap but the vast majority of groups defined themselves as activists and lobby groups - the latter being elaborated as lobbying for drug law reform, and against the stigmatization, discrimination and marginalization that are structurally built into the political, social and cultural environment in which drug users live. In another question 78.6% of the groups surveyed reported that they were "politically active" in the areas just referred to. The latter impression is reinforced when one examines the services that the various groups offer,;

Syringe patrol and distribution 64.3%
Advice on safe drug use/Harm Reduction advice 85.7%
 Help with treatment 64.3%
 Help with housing 35.7%
 Help with training 71.4%
 Nursing 21.4%
 Wound care and basic health care 57.1%
 Food 42.9%
 Legal aid 50.0%⁷

When combined, these statistics demonstrate unequivocally that the vast majority of the groups surveyed see themselves primarily as representing active drug users, and that whilst many of their members might also be enrolled in some sort of substitution programme, a positive drug using identity is dominant. This finding is reinforced by an examination of the responses to the question probing the kind of political activity that the groups are involved with (78% of the groups surveyed answered in the affirmative to the question “Are you politically active?”), where the responses were of a piece, and included “Lobbying, meetings, seminars and debate articles in order to change the war on drugs”, combating “policy and the stigma which drug users experience”, “fighting for a drug system much more fair”, and carrying out “evaluations to change political conditions”. When it came to the request to “describe your groups major goals”, the responses again were unremittingly of a political activist character, and demonstrated clear and unequivocal attention to the larger structural health and human rights iniquities that are unequivocally produced by the imposition across most of Europe of a punitive prohibitionist approach to drug questions, the answers displayed without exception that this is how the respondents understood the environment in which they operate, and underlined that advocacy for drug law reform must, and will be, top of the agenda for the nascent EuroNPUD. Sample answers were: “to change public perception of drug users/use which in turn could change local and national policy”, “to change the political-legal drug system”, “promoting dialogue and debate around the social phenomenon of drug use legal and illegal and demanding their normalization and legalization”, this latter theme was reiterated by another respondent as “acceptation, normalisation and legalisation of all kind of drug/use”, and “renunciation of abstinence paradigms and prohibition. The end of repressive and undignified persecution of drug possession, drug use and drug users”. Once again, when it came to the methods used to achieve these goals, it was clear that all groups saw themselves as peer organisations carrying out lobbying and advocacy work on the levels at which they are organised (whether that be city wide, within a region of a country, or as a national network).

The identity of the groups as organisations run by and for people who used drugs was further confirmed when we looked at governance structure, where apart from the encouraging fact that 100% of the groups who responded to the Questionnaire were governed by constitutions, and 84% had premises that suited their purposes, responses to the question: “Do you have to be a current or former drug user to hold an office in your group or can people who don't (or have

never) use(d) drugs hold office?” were almost uniform in stating that “Its fundamental: you must have the experiance about the issue you about to talk about”. This confirmed an almost universal adherence to the often used slogan “Nothing about us without us” and demonstrated a keen adherence to the principal of meaningful participation. In short, the groups surveyed were unequivocally run by and for people who use drugs. That said, some of the groups did allow supporters of drug law reform to perform administrative functions but not to take part in decision making processes. Approximately 90% of the groups responded that they did allow non-drug users to join, on the following basis:

Supporters of drug law reform 76.9%
Ex-drug users 92.3%
 Friends and family 53.8%7

In terms of membership breakdown, the most worrying trend we identified was in terms of the age breakdown of the membership, which was as follows:

Under 18 0.0%
 19-25 (inclusive) 42.9%
 26-30 (inclusive) 50.0%
 31-35 (inclusive) 85.7%
36-40 (inclusive) 92.9%
 41-45 (inclusive) 85.7%
 Over 46 57.1%

This clearly shows an aging population being predominantly represented, and the corresponding under-representation of youth and the need to reach out to and organise younger drug users was identified as being a priority at the Marseille meeting – strategies for such outreach were noted as an area in which much work is needed. In terms of the gender balance, it was abundantly clear that women are massively under represented in drug user organisations, again, this is an issue that needs to be addressed, especially given the specific issues that face women who use drugs. None of the groups mentioned having a strategy for remediating this imbalance, but it will clearly need to form a part of EuroNPUD’s agenda.

In terms of networking, 79% of respondents reported being in contact with other groups of people who use drugs (equally 100% of the groups surveyed reported having contact with local harm reduction organisations), and 71% of the groups had members active in INPUD. An encouraging 91.7% of groups who completed the Questionnaire responded “Yes” to the

question “Do you think belonging to a *European Network of People who Use Drugs* would help you?” this latter acted as a stern underpinning to the deliberations and decisions made at the founding conference, and acted a reminder of the considerable importance of those decisions to the already existing, informal network of people who use drugs in Europe and demonstrates unequivocally a desire for a European wide exchange of ideas, experiences, learning, and best practice, formalised in the *European Network of People who Use Drugs*. The reasons given for wanting such a network focused around the collective voice that a European network would give to the different national groups to get their voices heard at a European level, others referred to making “contact with experienced partners/organizations”, to increasing our ability to “put pressure on the European Parliament and other Euro institutions”, the same respondent went on to say that “we can use [progress in other countries] as an example to other European countries to follow, after all that’s how things usually work in Europe and we can use the European tradition in Human Rights and social democracies to change and develop their drug policies”, a very similar sentiment was expressed in these words: “a European network could help to support and stabilise. Contacts can be built up, an exchange of experiences can be maintained and cultivated [...] Working in a European network also provides important initiatives to realise personal values. This includes self-experience, the development of self-respect and feelings of self-esteem. In the next decades Europe plays a more and more important role (also in drug law) so a European network could do important steps to change the drug use and living conditions all over Europe.” As such, there is a very strong feeling that the development of a European network would be of benefit to the national groups in terms of strengthening our voice on the European stage – one of the action points decided upon at the founding conference was to register the network as a member of the EU Civil Society Forum on Drugs (at which INPUD is already represented), and the EU Civil Society Forum on HIV/AIDS.

With regards to the future development of the network, and the opportunity to bid for a second round of funds to do such development work, the data gathered makes it clear that as far as the founder members are concerned EuroNPUD should have three principal strategic objectives, this analysis was confirmed by the views presented at the founding meeting in Marseille:

- 1) Development of Europe wide advocacy on drug law reform
- 2) Country and regional advocacy in support of Global agendas with donor countries and the EU

- 3) Network strengthening with a view to developing drug user organising in countries where it does not currently exist; supporting such organising in those countries and regions where it is weak and under developed.

The process of network strengthening is the backbone upon which the two preceding objectives are based, as such and in order to develop our advocacy agenda, EuroNPUD will establish an internet based discussion forum, as well as several working groups to develop and progress these objectives. EuroNPUD already has a solid basis upon which to build, and in some respects, the official formation of EuroNPUD is just the formalisation of the already extant, albeit weak, and informal networking that is already happening amongst local and national organisations of people who use drugs. Through the astute use of social networking tools, and development of a concrete agenda, combined with network strengthening, it seems that EuroNPUD is well placed to accurately and forcefully galvanise and represent the interests of people who use drugs on a pan-European level.

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