# Correlation

European Network
Social Inclusion & Health

# Who's afraid of science?

## Data collection, quality standards and evaluation

## -Examples from Europe

Newsletter 2/ 2013

www.correlation-net.org

# Colophon:

De Regenboog Groep

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# Welcome to newsletter 2/2013!

Many NGO's and grass-root services have indicated, that they have insufficient knoweldge, expertise and skills to document, monitor and evaluate their services. This is particularly unfortunate, because sponsors and funders often expect agencies to operate according to evidence-based methodolgies. We also know that documentation, monitoring and evaluation contributes to the quality of services.

In this newsletter we have tried to give an overview of what can be done in this field, by particularly taking into account the limited resources of NGO's.

Furthermore, we give attention to data collection, the development of European quality standards in harm reduction and prevention services and present an example how data collection can be organised.

Many thanks to all authors involved.

More info can be found at the Correlation website: www.correlation-net.org

Till soon,
The Correlation Team

# Content

# 1. Who's afraid of science? Research and evaluation for grass root organisations

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Evidence Based Interventions, Randomised Controlled Trials, Double Blind Evaluation Protocols, Social Epidemiological Research - scientific principles that scares you off working in the field. Although very useful, scientific standards like these are often unreachable for grass-root workers. Evidence Based Interventions seldom are available for your specific target group and problem or they don't fit properly. Randomised Controlled Trials are very complex and expensive. Social Epidemiological Research takes too much time for a quick response on a new health-risky trend. Nevertheless not only researchers but also policy makers and large scale service providers put emphasis on those scientific quality standards. That doesn't encourage grass-root workers and small service providers to do assessments or self-evaluations. It frightens to stand up against those standards. That is a pity because a lot of knowledge and understanding of practice and development in the field is lost. **But luckily there are also science based methods available that can help you with less costs, efforts and complexity to evaluate your work and projects.**

Although Evidence Based Interventions are the highest standard – it's the best you can get – there are not that many Evidence Based Interventions available, especially not in the field of social inclusion and health for vulnerable and marginalized groups.
**Evidence base means that the intervention is based on a scientific theory and has been tested thoroughly in different places and under different circumstances.** That is a lot of work and consumes a lot of money. Second best thing is a Best Practice. This hasn't scientifically been proved to be the best but according to experiences it is the best the field has to offer at the moment. Best practices are mostly based on self-evaluation of existing projects. It becomes interesting when those experiences are collected from different projects that use more or less the same intervention on the same issue and with equal target groups. It is practice based and the more field projects are involved the more it moves towards Evidence Based Interventions. Within the Correlation Network Best Practices have been collected among field projects all over Europe, for example on outreach, peer work, hepatitis C and other subjects in the field of social inclusion and health. They can be found and downloaded on the website of the Correlation Network.
**The strength of Best Practices depends on the quality of the evaluation of the field projects/interventions involved.** Here the highest standard for project evaluation are Randomised Controlled Trials. They use several control groups and double blind protocols so both researchers and participants know only after the trial who had what treatment. That is almost impossible to integrate in daily practice. But there are a lot of other ways to do proper but simple evaluations, whether it is to develop Best Practices or just to evaluate your own project.
**The most simple but rather effective way to evaluate your activities is inter-vision.** It simply means that you ask a colleague's opinion on what you are doing. You can make that stronger by inviting him to join you on the job one day, or more often, maybe systematically every once a week and maybe you can involve the opinions of other colleagues etcetera. You can expend that as much as you like and make it stronger and stronger.
There are several scientific means that can be used to improve the quality of your evaluation. **Data triangulation for example means that you try to collect information in different ways and from different sources.** You can ask the opinion of several colleagues instead of one, you can include the opinion of target group members or significant others closely involved with your project. You can combine different methods like interviews and questionnaires or focus group interviews. **The more different angles and methods you use the stronger your evaluation gets.**
Induction is another scientific principle that fits in here. It simply means that the more answers or opinions are the same the stronger the answer is. The more colleagues, target group members and others involved state that you are doing a terrific job the more plausible it is that you really are doing a terrific job. But what is a terrific job? The next challenge is to describe what you are doing on the job the best way you can.

**What exactly is your target group and problem? What are the aims of your project or intervention? And how can you reach your aims?**
Several scientific but easy to use instruments can help you out. You can describe your aims in terms of indicators. That makes it possible to measure whether and to what extend you reached your aims. Indicators must be **SMART**. This means they have to be **Specific:** what exactly do you want to reach? They have to be Measurable: what do you want to measure, how can you measure that? Can you in some way feel, see, hear or smell it? Indicators have to be **Appropriate:** it has to be acceptable for both the target group and the project partners, everyone involved must feel good about it. They have to be **Realistic:** there must be a reasonable chance that you can reach your aims. If it is too difficult, it's frustrating, but if it is too easy, it kills motivation. And of course, indicators have to be **Time-bound:** there must be a certain time limit. When does it start? When does it end? Deadlines must be realistic.
It helps a lot to think about how and with what instruments you can measure your indicators. Is there already information available that you can compare later? Are there health statistics about your target group? Are there research reports available? During the project you can use client records or training registers, you can make logs. You can get information from the field by interviews, focus groups or observations. If you have thought about that, it will be easier to make your indicators SMART.
Now that you have described your project, aims and measure instruments you have to choose an **evaluation design.** Most simple thing is to implement your intervention and after a certain time look back. That is called a single-measurement. It tells you what happened during the project and gives you ideas to adapt it. **With a baseline- end-line design you can measure changes that happen during you project.** You do a measurement before you start the intervention and again a while after the project has been implemented. By using the same instrument (a questionnaire for instance) before and after the intervention you can measure the changes over time.
If you want to know whether those changes are due to your project and not to other, external factors you can use control groups. You can easily divide groups in treatment or no treatment. This gives evidence that the effect of the intervention is exclusive for that part of the target group, that was served by the intervention. **Be aware that it can be an ethical dilemma to exclude groups from treatment.** In that case you can use regular treatment and some new specific treatment. That gives you evidence that a specific treatment has another effect than regular treatment. If you can combine no treatment – regular treatment – specific treatment you get even stronger evidence for the effect of the specific treatment.
Of course it depends on time and resources available whether you can do only a simple evaluation or use a control group design etcetera.

Correlation currently establishes a specific section on the website where you will find related documents, links and resources.

www.correlation-net.org

# 2. EMCDDA - Assuring quality in harm reduction

Marica Ferri
EMCDDA

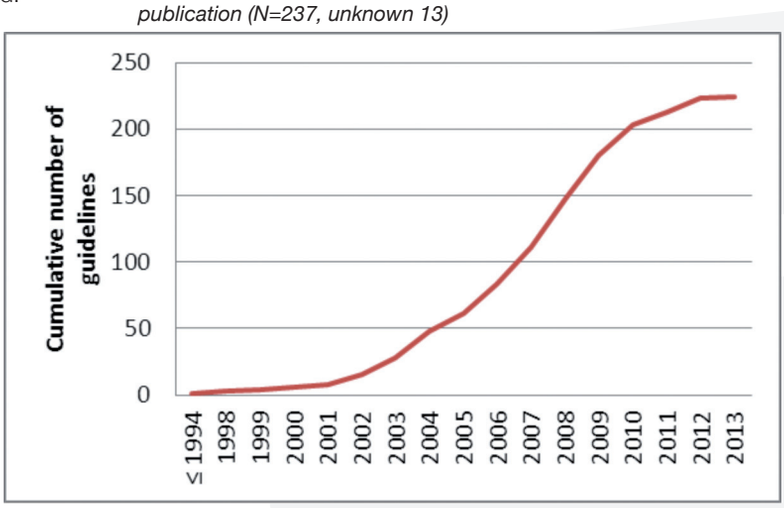
The European new Drug Strategy and Action plan, reiterate that policy should be based on evidence and that Best Practice in drug demand reduction are to be identified and promoted. This appears to be the focus which strongly characterizes the European approach to drug related problems. The European Monitoring Centre for Drugs and Drug Addiction has been working to fine tune the dissemination instruments for the promotion of Best Practice across Europe and beyond.

As a first step the EMCDDA provided a definition of Best Practice in drug demand reduction. **In brief, best practice is the best application of the available evidence to current activities in the drugs field.** A number of factors were identified as contributing to making an intervention qualify as 'best practice'. In summary, a best practice intervention is based on the most robust scientific evidence available regarding what is known to be effective in producing successful outcomes, and it is tailored to the needs of those it addresses. Methods used will be transparent, reliable and transferable and can be updated as the knowledge base develops. With regard to implementation, local contextual factors will be taken into account and the intervention will be harmonised with other actions as a part of a comprehensive approach to drug problems(Ferri and BO, 2012).

The main output for the dissemination of Best Practice at EMCDDA is the **Best Practice Portal** which includes synthesis of the available evidence with an inventory of European Guidelines and standards, and examples of projects for prevention, treatment and social reintegration and harm reduction.

It is clear that to obtain beneficial results for the clients, not only the interventions are to be evidence-based but also they need to be provided according to virtuous processes. Guidelines are the consecrated support to recommend evidence-based interventions to practitioners whereas the standards are becoming popular tools to promote the management of interventions and doing so, to promote the quality. The majority of European Countries have currently guidelines for drug demand reduction and the first examples date back to 1960 addressing treatment (figure 1).

*Figure 1. Cumulative number of guidelines (about treatment, prevention harm reduction and social reintegration) by year of publication (N=237, unknown 13)*



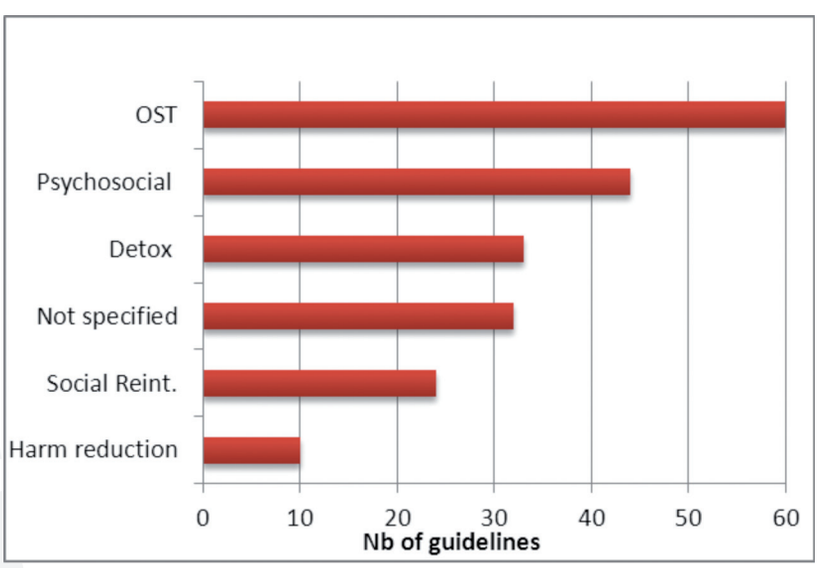

Recently the European Union as a whole and some European Countries have developed or they are in the process of developing quality standards for drug demand reduction interventions.

**Guidelines** have been defined as: 'statements that include recommendations intended to optimise patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options' (Institute of Medicine, 2011) and standards are intended as principles and sets of rules based on evidence (Brunsson and Jacobsson, 2000), used to implement the interventions recommended in guidelines. Traditionally quality standards have been divided

in three broad portions focusing on structure, process and outcomes (Donabedian, 1992).

The availability of guidelines explicitly devoted to Harm Reduction is lower than those for Treatment or Prevention **(8 Countries reported to the EMCDDA to have a set of guidelines for Harm Reduction)** but this information has to be considered with caution because most of the published guidelines are on opioid substitution treatment and may include also recommendations for harm reduction (figure 2).

*Figure 2. Content of treatment guidelines (selective sample N=62)*




At European level a joint guidance on the prevention and control of infectious diseases among people who inject drugs (Busch et al., 2013) is a reference document for some interventions of harm reduction among injecting drug users (all the mentioned guidelines are available in the Best Practice Portal).
The European Project EQUS (Minimum Quality Standards in Drug Demand) had the objective of finding consensus on a minimum set of quality standards in Drug Demand Reduction and it identified 16 quality standards in harm reduction.

The standards were originally extracted from a list of Guidelines and subsequently submitted to the collaborating project partners in an expert seminar and then to 514 stakeholders from all Member States in two on-line surveys. The participant stakeholders rated the proposed standards as already implemented, acceptable without problems, acceptable with problems or unacceptable. The ratings resulted in separate lists of minimum quality standards with high consensus of acceptability (<80% of acceptance), with moderate consensus (50-80% of acceptability) and low consensus (>50% of acceptability).
Among the standards rated higher for consensus, three were structural standards. Structural standards are those defining desirable characteristics of the physical place and education of personnel delivering some intervention.

**The standards identified by EQUS were related to accessibility:** to ensure that the choice of location and opening hours match the needs of clients and avoid that costs become a barrier for service. As far as for the staff qualification, it is requested that staff is qualified and qualifications are declared and updated with new relevant knowledge in their field. Furthermore no age limits should be set to access harm reduction services and staff should be trained to meet age specific needs of clients.

**The standards regarding the process, are those determining the sum of actions that make an intervention from the beginning to the conclusion.** The European project recommended standards for the assessment of possibly risky behaviours and for a prioritization of objectives, for example “1. Harm reduction of intravenous drug use and, 2. Reduction of

emcdda

used syringes in public spaces". In addition, the assessment of the clients´ health status is suggested along with the informed consensus. Clients should be informed about the available service options and agree with a proposed regime or plan before starting an intervention. It is specified that for the respect of the clients' privacy the informed consent should not be kept as a written record. Directly linked to the latter specification is the recommendation to ensure complete confidentiality of any data regarding the clients which should be made accessible exclusively to the staff involved in the intervention.

**The interventions should be planned to match the individual needs of a client and for addressing those needs in a holistic way, routine cooperation with other agencies is to be sought.** The neighbourhood and community should be consulted to ensure cooperation and to avoid nuisance and conflicts.

Outcomes standards are to some extent the most difficult ones because the connection and causal relation between the process and outcomes can require complex analysis. On the other hand they are the most relevant because the ultimate goal of quality is to provide good results for patients. The project proposed one real outcome standard and three more that could have been considered process standards. The pure outcome standard indicates the reduction of risk behaviours (including injection, unsafe drug use and unprotected sex). The remaining standards are about referral of patients to other services to better meet needs and external and internal evaluations.

Suggestions on the areas to be improved for harm reduction in Europe, came from the recently published Report on the current state of play of the 2003 Council Recommendation on harm reduction (Busch et al., 2013). The report, commissioned as an evaluation of the impact of the Council Recommendation after 10 years, concludes that **"The Council Recommendation (CR) helped foster harm reduction in the EU, but the coverage is still far from sufficient in most areas " and identifies three priorities for further efforts. These priorities are the reduction of drug induced deaths, the improvement of harm reduction in prison and reduction of harm caused by drug-related infections.**

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# 3. The European Drug Prevention Quality Standards

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## Introduction

This article provides a brief review of the work with respect to the development of European Drug Prevention Quality Standards which is being undertaken by the European Drug Prevention Standards Partnership and led by Professor Harry Sumnall at the Centre for Public Health at Liverpool John Moores University.

The aim of this two phase initiative is to provide guidance and support to those working in the European drug prevention community and to promote awareness and application of high quality policy and practice.

Phase I of this work was completed in 2010 under the project name "European standards in evidence for drug prevention". The resulting Prevention Standards were published by the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) in 2011. (see http://prevention-standards.eu/wp-content/uploads/2013/06/EMCDDA-EDPQS-Manual.pdf to download a copy.)

Phase II entitled "Promoting Excellence in Drug Prevention in the EU – Phase II of the European Drug Prevention Quality Standards Project" began in April 2013 and is a 2 year initiative of the Partnership that will report in May 2015.

## How can the European Drug Prevention Quality Standards be used, and what is their intended purpose?

- The Quality Standards help users understand how people, programmes/interventions, organisations, and (governmental) strategies contribute to drug prevention, and to think about how existing efforts can be improved in order to obtain better and more sustainable results. Drug prevention work in line with the Standards is characterised by an evidence-based approach, internal coherence, and an orientation towards both policy and participants.
- The Standards are applicable to a wide range of drug prevention activities (e.g. drug education, structured programmes, outreach work, brief interventions), settings (e.g. school, community, family, recreational set tings, criminal justice), and target populations (e.g. young people, families, ethnic groups). Drug prevention activities targeted by these Standards may focus on legal and/or illegal substances. Phase II will produce case studies of how specific examples of drug prevention activities in the EU could benefit from using the Standards.
- The Standards will be of interest to all those working in the prevention community. These individuals are likely to be involved in one or more of the following activities: policy- and decision-making; service management; front-line work/ work in direct contact with the target population; training; supervision; programme development; consultancy, evaluation and/or academic research. A range of toolkits will be produced as part of Phase II which will be targeted towards specific groups (e.g. practitioners, policy makers) and their everyday needs.
- The Standards can be used for a range of purposes; including: information, education and guidance; self-reflection; discussion in group settings; performance appraisals. Further work is being undertaken through Phase II to make the Standards useful for other purposes, such as formal self-assessment, funding decisions, or external accreditation.

## Phase I of the European Drug Prevention Quality Standards Project

### *Why were the European standards developed?*

When the project began in 2008, drug prevention quality standards were available only in some Member States of the EU. The available guidance varied in terms of its content, methodological rigour, and applicability beyond the regional/ national context. Consequently, a common European framework on drug prevention was missing. It was also not clear to what extent internationally available guidance was relevant to drug prevention in Europe, and how it could be adapted to the European context (for example, the "Standards of Evidence" published by the USA Society for Prevention Research in 2004).

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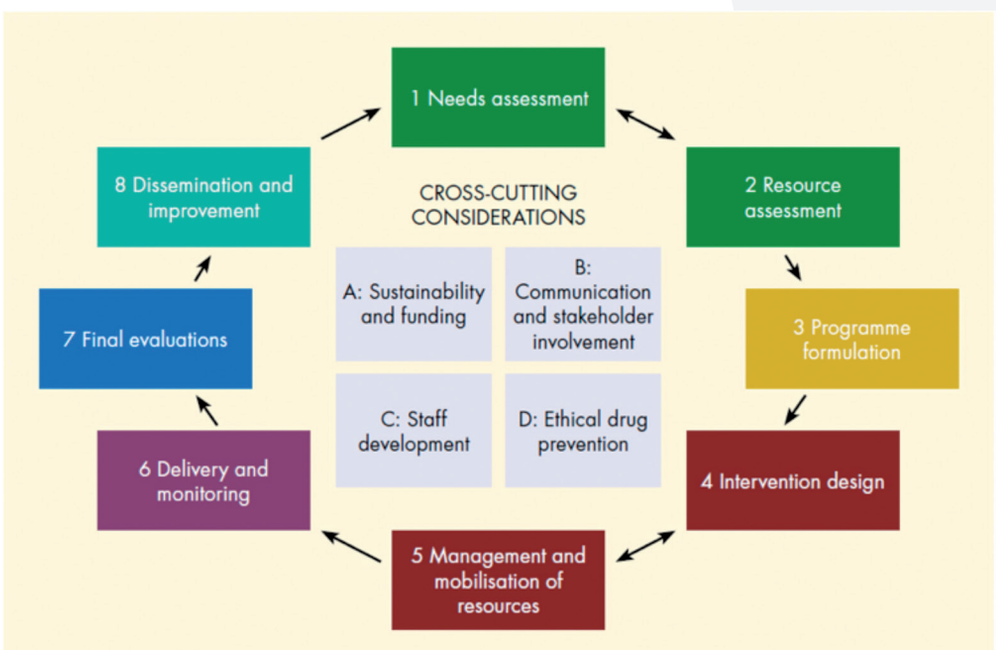
The need for a European drug prevention framework was apparent in EU policy documents, such as the EU Drugs Action Plans. These had expressed an intention to develop and implement best practice in drug prevention, but without being able to provide a reference framework on how to do this. The Prevention Standards Partnership, a multi-disciplinary and multi-sectoral collaboration of partner institutions in six EU countries, was formed in response to this situation.

Objectives

Phase I of the European Drug Prevention Quality Standards ('Prevention Standards') project aimed to provide an empirically derived reference framework to bridge the gaps between science, policy and practice. The specific objectives of Phase I were to compile, review and analyse existing drug prevention standards in EU Member States, and to publish a common set of European Drug Prevention Quality Standards. The Prevention Standards which were developed offered the first European framework for high quality drug prevention. Organised in an eight-stage project cycle, the Standards outline the necessary steps in planning, implementing and evaluating drug prevention activities.

Figure 1: Project Cycle




The Standards were published in December 2011 by the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) in its Manual series. The official launch took place on 9th December 2011 in Lisbon, Portugal, at the conference of the European Society for Prevention Research (EUSPR). The Standards are available for free for electronic download and to order from the EMCDDA website - see http://prevention-standards.eu/wp-content/uploads/2013/06/EMCDDA-EDPQS-Manual.pdf

## European Drug Prevention Quality Standards Phase 2

The availability of an agreed framework that is adaptable to local circumstances is intended to provide an incentive for EU Member States to develop quality standards where these did not previously exist, or to review and update existing quality standards, and adopt the Prevention Standards for their own use. Adoption of the Standards is aimed to improve drug prevention practice and efficiency of funding, and reduce the likelihood of implementation of ineffective and iatrogenic interventions. Thus, the Standards will support the fulfilment of local, regional, national and international drug strategies and policies.

Although some members of the prevention community have already started applying the Standards successfully in their work, the structured consultations undertaken during Phase I indicated that without widespread dissemination of the Standards, their positive impact will be limited. Further activities to facilitate and promote uptake of the Standards in practice are needed.

Phase II of the Prevention Standards project is currently underway to address this challenge by developing supporting materials and demonstrating how the Standards can be applied in practice.
With this focus in mind, Phase II of the project started in April 2013 in order to develop activities, including the provision of supporting materials for a wide range of drug professionals. Phase II of the project is now under-way, again led by Prof Harry Sumnall of the Centre for Public Health at Liverpool John Moores University, UK, with an extended Partnership comprising 15 partner organisations within Europe.

**Objectives and activities during Phase II**
The objective of Phase II is to develop practical tools and training which will facilitate the integration and implementation of the European Drug Prevention Quality Standards, and also to strengthen a consensus within Europe on what 'high quality drug prevention' is. The target audience will be all working in the drug prevention community, particularly the prevention providers, practitioners and policy makers.

**The specific objectives of the Prevention Standards Partnership in Phase II are:**

- To demonstrate how quality standards in drug prevention can be achieved and evidenced in practice, taking into account differences in prevention culture, structure, policy and practice between settings and countries;
- To present the Standards in a user friendly way through the production of a number of toolkits targeted at different professional audiences and customisable according to different needs;
- To support the development of professional attitudes and skills relating to evidence based prevention among the prevention workforce, thus increasing consensus and acceptability of quality standards (including the EQUS drug demand reduction standards) and evidence based approaches to prevention;
- To establish the European Drug Prevention Quality Standards as a recognisable 'brand' among the European drug prevention workforce and promote their use internationally;
- To identify ways to sustain the use of the Prevention Standards through incorporation into established training programmes, university courses, and investigation of follow-on sources of funding.

**Activities**

To achieve this, project partners will undertake a number of activities, organised in two Work Streams . Relevant information from other centres of expertise and other work in the area of quality standards at the national and international levels will also inform these activities.

**Work Stream 1:**
**Application of Quality Standards (April 2013 -Overview of project activities December 2013)**

- Case studies of particular prevention work in six EU countries
- Mapping and review of existing indicators and quality assurance models in drug prevention and health promotion
- Development of bespoke indicators which will allow to work towards and demonstrate achievement of the European drug prevention quality standards

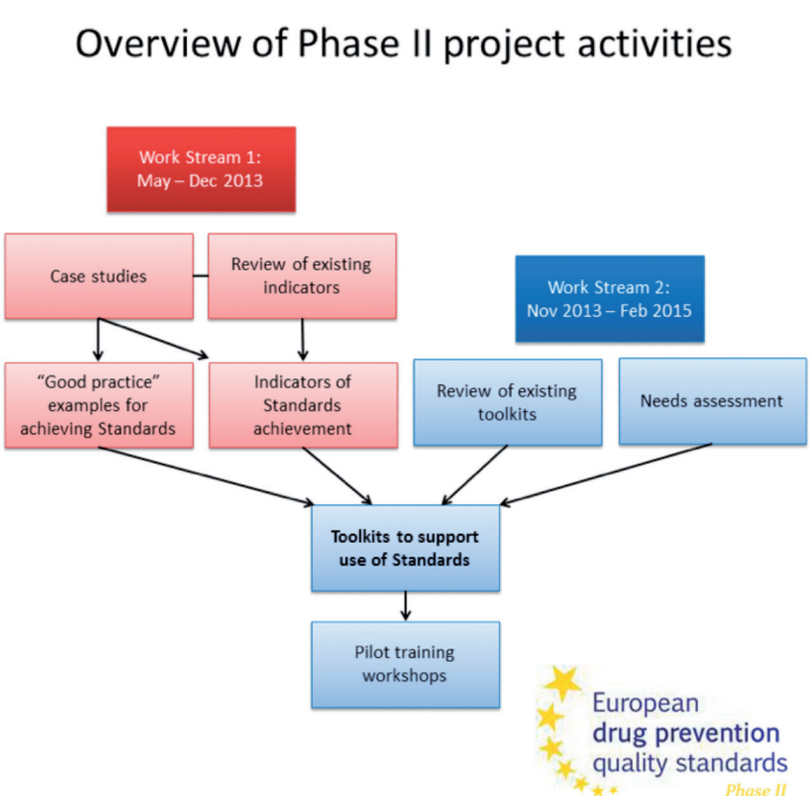



Figure 2: Phase 2 workstreams

**Work Stream 2:**
**Development of toolkits (November 2013 – February 2015)**

- Mapping and review of existing toolkits in drug prevention and health promotion
- Needs assessment to identify relevant target udiences for toolkits
- Development of toolkits and training materials
- Pilot training workshops with commissioners

**What can you expect from Phase II?**

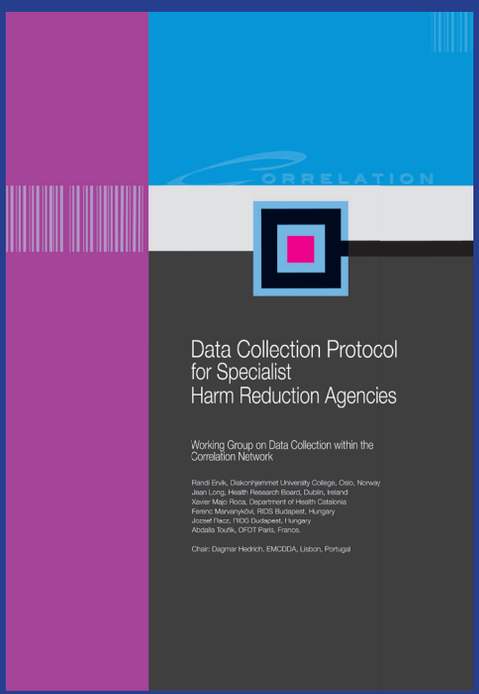
The project will produce materials that will provide significant support to all those working in the prevention field, including:

- Practical "toolkits" for helping the target audiences apply the Standards in their work
- Training and "train the trainer" courses for different prevention providers and policy makers
- Expert publications on specific issues related to quality standards in prevention
- Indicators to help provide evidence for the achievement of the Standards
- Support materials to help in applying the Standards to current practice.

The project will help prevention professionals develop their work in accordance with sound principles and evidence, and – as in Phase I – aims to make a major contribution to promoting health and well-being in European populations.

The European Drug Prevention Quality Standards project is co-funded by the European Union under the European Commission's DG Justice "Drug Prevention and Information Programme" (DPIP).

# Data Collection Template:




This booklet has been complied by **Correlation** and describes the development and the field testing of a data collection protocol for harm reduction agencies and presents the final tool, including a manual.

You can find additional information and the inventory on

www.correlation-net.org/products

# 4. Quality Action: Practical Quality Improvement for HIV Prevention

Matthias Wentzlaff-Eggebert
Federal Centre for Health Education
Germany

**Are we focussing on the right target groups?**
**Are we using the most promising approach?**
**Are our methods 'good practice'?**
**Is the scale of our program or project large enough?**
**Have we included all important stakeholders?**

Finding clear evidence to inform even these basic decisions is sometimes difficult. Still, we decide as best as we can and conduct a wide range of HIV prevention interventions to improve health outcomes.

But when the impact is less than we expected or hoped for, how do we know why? Did we choose the wrong target group, an inappropriate approach, a less than effective methodology? Did we do all the right things, just not at a sufficient scale? Was it a good plan implemented poorly or a bad plan implemented well? And even if the results are excellent, can we pinpoint the reasons why?

This new EU co-funded Joint Action unites 42 NGO and government partners across 25 member states to increase the quality of HIV prevention in Europe. **Effectiveness in prevention is hard to analyse and measure, let alone influence directly. Quality in implementation as a key factor in effectiveness is attracting increasing attention.**

Quality assurance and quality improvement (QA/QI) are common in many industries and services, from manufacturing to surgery. They ensure that the work is carried out at the highest level of quality possible in a given context. Because QA/QI shows whether it was done well enough, results can be confidently linked to the work itself.

- **Quality Assurance** monitors the quality of services and activities against certain standards. It usually includes review, problem identification and corrective action.
- **Quality Improvement** identifies, implements, and evaluates strategies to increase the capacity to fulfil and exceed quality standards.

**In HIV prevention too, it is not enough to do the right things, we need to 'do the right things right'.** However, because human behaviour is influenced by complex psychosocial, socio-political, economic and structural factors, applying QA/QI is not quite as straightforward.

Over the past several years, an international group of NGO, government and academic experts collected and adapted practical QA/QI tools for use in HIV prevention. The work and approach of the IQhiv initative (www.iqhiv.org) resonated with policy makers and NGO stakeholders at European level and forms the basis of Quality Action, the current three-year co-funded project that started in March 2013.

The German Federal Centre for Health Education (BZgA) in Cologne, Germany, acts as coordinating partner and works in close collaboration with 24 associated and 17 collaborating partners in 25 member states. BZgA is a statutory body under the Ministry of Health that develops scientific advice and implements national disease prevention and health promotion strategies, including HIV prevention.

**Quality Action takes an empowering approach to quality, encouraging HIV prevention teams to self-reflect on their work and increase the participation of their stakeholders in making improvements: projects own their QA/QI results and decide who they share them with.**

Improving quality is already part of the project cycle in most teams. But often it takes place inside the minds of individuals, it isn't shared, checked or documented. Good ideas are lost because there is no time or structure to capture them and use them more widely. This is what the practical tools are for.

**Quality Action offers five practical QA/QI tools adapted to HIV prevention to choose from (one is designed especially for harm reduction with people who inject drugs).** The tools are questionnaires and facilitation guides to help teams improve quality consciously, deliberately and systematically. The project also trains at least 60 trainers/facilitators in the participating countries to apply the tools to their own programs and projects and to assist others.

# 9 Reasons to get involved in Quality Action:

1. Become aware of what you are already doing well
2. Learn about when, how and why you are already successful (and sometimes fail)
3. Get new ideas on how to improve what you are doing
4. Increase participation and benefit from stakeholder input
5. Provide yourself with space and time to reflect on your work and build on your team and internal communication
6. Enhance your co-workers/employees' work satisfaction
7. Build different types of evidence that supports your HIV prevention interventions
8. Simplify and enhance the planning, implementation, monitoring and evaluation of your projects and programs
9. Network with other European organisations in make HIV prevention more effective.

At least 80 such practical applications of a QA/QI tool are the core of the project. Quality Action will use the results not only to revise the tools and training materials, but also to document the emerging quality principles and criteria in a 'Charter for Quality in HIV Prevention'.
Literature and practical experience already articulate some common factors for quality, e.g. involving the target group and defining measurable and achievable goals and objectives. The Charter will include additional principles and criteria that emerge from different teams applying the tools to their programs and projects across Europe. A Policy Kit with recommendations and strategic actions to integrate quality at national and sub-national levels complements the Charter.

Not only Quality Action partner organisations can access the tools and participate in their practical application. **If you are interested, go to www.qualityaction.eu and follow the menu to 'get involved'.** Quality Action offers a range of ways to benefit from its activities, from subscribing to the newsletter or simply using one of the tools to joining as a collaborating partner and contributing to the results and the Charter for Quality in HIV prevention.

BZgA
Bundeszentrale für gesundheitliche Aufklärung

# 5. Example Imp.Ac.T. - Improving Access to HIV/TB testing for marginalised groups

Nadia Gasbarini
Fondazione Villa Maraini
Italy

The general objective of the project Imp.Ac.T. was to broaden the access to HIV and TB testing, prevention, treatment and care for vulnerable groups, such as drug users (DU's) and migrant DUs. The project was co-funded under the EU health program 2008 - 2013 and was coordinated by Fondazione Villa Maraini. Partner were Sananim (CZ), Odyseus (SK), Guppo Abele (It) and Foundation the Rainbow Group (NL).

The project's specific objectives were:

- To develop a framework and model to improve the effectiveness of HIV and TB testing and counselling among DUs and migrants DUs;
- To increase the percentage of DUs and migrants having access to HIV and TB testing;
- To ensure that people living with HIV and TB receive teatment for both conditions;
- To promote healthier ways of life and risk reduction among drug users and migrants;
- To assess the effectiveness of street HIV and TB testing in terms of proportion of new infection identified.

**The Imp.Ac.T. project has used outreach work as a tool for promoting a new kind of provider-initiated counselling and testing, combined with low-threshold services for DUs and migrants.**
A common methodology has been developed and used by all partners, both for the implementation of the testing and for the assessment of its effectiveness. This has been done through the organization of workshops and meetings among the project partners and several consultations with local and international experts.
Before starting the testing uptake, each organization conducted a training course for its own team, using the manual jointly developed by all the partners. The trained staff carried out HIV and TB testing among DU's (with special focus on problematic drug users and migrants) attending low-threshold services managed by each partner organization (needle exchange points, street units, drop-in centres, night shelters, substitution treatment programmes). The target group was provided with information leaflets on HIV and TB infection, the aim of the project, the procedures of testing, the respect of anonymity and privacy; those accepting to be tested have been asked to give the informed consent (written or verbal, according to the local rules) and then, have been provided with pre-counselling and HIV rapid test (DETERMINE HIV 1-2) and a clinical screening for TB. The clinical screening has been conducted by health professionals (doctors or nurses) in order to identify suspected cases with TB symptoms (prolonged cough, fever, chest pain, breathlessness, loss of weight, fatigue) or with other risk factors (HIV-positivity, contacts with TB infected patients, etc.). **These identified cases have been requested to give a sputum sample to be sent to clinical centres for laboratory examination.**
Those clients resulted preliminary positive to HIV test and TB sputum analysis have been referred to specialized clinical centres for confirmatory testing and eventually, treatment.
In order to ensure clients follow-up and facilitate access to treatment for those in need, HIV and TB clinical centres have been involved as collaborating partners of the project, for regular exchange of information on the clients referred by the partner organization.
During the pre-test counselling or while waiting for the HIV rapid test result, a questionnaire has been administered to clients, in order to collect data on lifestyle behaviours, health conditions and history of HIV and TB testing.
**All demographic, epidemiological, clinical and laboratory data collected by each partner have been entered in an online database and analyzed by a researcher with the aim to assess the effectiveness of this kind of intervention in terms of increased access to testing for vulnerable groups and number of new identified infections.**

In total, 4.855 persons have been approached, of which 2.352 have been interviewed and tested. Nearly 2.200 were problematic drug users (PDU's). **This on itself is a success and provides us with new and vital information on the situation of DU's in Europe, the HIV and TB prevalence and incidence rate among DU's and the (perceived) barriers for DUs to access HIV and TB testing, treatment and care.** Almost 20% of the people tested were never tested before for HIV: these data show that the

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provision of testing in low-threshold services has been useful and effective for reaching hard-to-reach groups. **Moreover, this means that the project has contributed to increase the number of persons tested and notifing TB and HIV cases among those unaware.** We have found 19 HIV reactive cases, of which 15 were active IDU's. For active IDU's, the newly diagnosed cases within the project reached 1%. The largest number of positive cases (18 clients) came from Italy; only one HIV positive case was found in Bratislava, none in Prague. Although TB might not be a problem among DU's in the four participating cities, it has been useful to collect these data. There was a lack of knowledge and information and the project created more evidence and more awareness about TB among outreach workers and the target group. Furthermore, experience has been gained in using our testing methodology, which is useful knowledge for future projects. Indeed, it was managed to develop a methodology to which all partners could comply and that could follow all required medical criteria but maintaining the 'rules' and working methods of outreach and low-threshold settings. This was a unique approach which offered the opportunity to reach a large number of target group members and collect a rich dataset. **Imp.Ac.T. has been a valuable example of a combination of 'street intervention' and data collection.** The fact that interviews were done by social workers sometimes improved the relationship with clients, but was also difficult in terms of 'role switching', since some workers experienced problems in combining their work as social worker with the role as interviewer and data collector.

Of the primary project objectives, three out of five were largely reached:

- A framework and model for effective HIV and TB testing among vulnerable groups in low-threshold services was developed;
- The percentage of DUs having access to HIV and TB testing was increased;
- The effectiveness of street HIV and TB testing in terms of proportion of new infections identified, was assessed.

As for the other two objectives, treatment for people living with HIV and TB was promoted and encouraged, as well as healthier ways of life and risk reduction among DU's. The cooperation between low-threshold facilities and clinical centres has facilitated the access to treatment and care for HIV and TB positive individuals, who didn't have any contacts with health services before. However, the follow-up resulted to be very difficult and it was not possible to accomplish this with all the clients.

Finally, the project has contributed to develop a new accurate and comparable registration system for assessing and monitoring the trend of HIV and TB infection among DU's and migrants. **The questionnaire and online database for data collection and recording have allowed to have a standardised reporting system** that can give a more reliable overview of the HIV and TB epidemics among most-at-risk groups both at national and European level.

For the training manual on HIV/TB rapid testing and other publications, please go to
http://www.projectimpact.eu/key_publi.html

Imp.Ac.T.
Improving Access to HIV/TB testing for marginalized groups

# Are you

- **an individual or part of an organisation engaged in the field of social inclusion and health?**
- **working on grass root level, as a service provider, in a research or policy institution?**
- **interested in knowledge exchange and collaboration on european level?**
- **advocating for fair and inclusive services and participation of affected communities?**

**Then you should join the network at**

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