

A Practical Guide to Developing Evidence-based Information on Drugs for the Internet

TRIMBOS INSTITUTE

This publication was made possible with co-funding of the Programme of Community Action for the Prevention of Drug Dependence, the Netherlands Ministry of Health, Welfare and Sports and the Portuguese Ministry of Health.

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Print

Resolutie, Capelle aan de IJssel

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ISBN: 978-90-5253-570-8



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ACKNOWLEDGEMENTS

The EELDA project is a collaborative effort of the Trimbos Institute, the Portuguese Instituto da Droga e da Toxicodépendencia (IDT), DrugScope (UK), supported by subcontractor Minervation Ltd. From 2003 to 2005, a multidisciplinary expert team from the project partners have shared experience, skills and know-how to develop the contents and structure of the EELDA website.

The authors wish to thank all EELDA staff and experts involved in the development of the EELDA website and this practical guide for their contributions, without which this publication could not have been written.

Maurice Gallà, project coordinator
Trimbos Institute

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INTRODUCTION

This practical guide is written in the framework of the development of the Evidence-based Electronic Library for Drugs and Addiction (EELDA), a website containing evidence-based summaries on key aspects of illicit drugs, including effects, risks, prevention and treatment.

The purpose of this guide is to document the experiences gained and the processes developed and followed in the building of the EELDA website and its contents. It contains a description of the development of the EELDA website but will hopefully have an exemplary function to those who plan to set up similar initiatives.

The information on the EELDA website is aimed at professionals but also at members of the general public who have an interest or involvement in drug-related matters and addiction issues and who are in need of reliable and up-to-date information on different aspects of the illicit substances covered.

This guide also aims to actively promote the transfer of knowledge, skills and experience on making evidence-based scientific information about drugs available to a broad group of professionals. Specifically, this manual aims to provide a first introduction into the development process that is required to publish synthesised, reliable and evidence-based information on commonly used illicit drugs on the internet. By doing so, it contributes to the promotion and dissemination working methods to produce evidence-based information among professionals in the field of addiction care and prevention.

This manual is not exhaustive or a blueprint for a complete project. Every initiative to produce evidence-based information for the internet is only as good as the relevance of its aims, the needs of its target groups, the skills and knowledge of the workforce involved and the access to and availability of information and technology resources. Therefore this guide should be seen as an example of good practice.

Preparation and management

1



INTRODUCTION

In practically all EU Member States websites containing drug information exist but these are often not evidence-based. Furthermore, many existing websites and information resources are developed by unknown web authors and organisations and/or contain a mix of (semi-) scientific information, which may sometimes be biased and include personal experiences and/ or opinions. Many sites are not frequently updated even though new evidence emerges on a regular basis. In recent years initiatives have been undertaken to map the many different websites and assess their content. One example is the ‘Elisad Gateway on alcohol, drugs and addictions’ project¹. Many good resource publications on evidence-based drug information are available on the internet, but these are not always easy to find or easy to read for non-researchers.

For people who are confronted with or involved in drug-related issues from a professional perspective, e.g. drug-experts, drug prevention workers, nurses, the police, policymakers, social workers, drug helpline counsellors and teachers it is difficult to find accessible and reliable information on drugs and addiction. Even general practitioners often do not have the time (or access) to search in the international scientific databases and journals on public (mental) health, prevention and addiction. And even if they do, many of them do not possess (up-to-date) skills to appraise the quality of scientific research. Interested members of the public, including drug users themselves, family, parents, students, etc... face the same problem.

The question what these potential visitors would like to find on a website such as EELDA was examined by assessing the type of information that is available on popular drug information websites and by assessing what some of the main categories of questions are that are received by the drug information help lines in the UK, Portugal and the Netherlands as well as the profile of the people that asked them. This provided insight in the type of questions professionals and the general audience have, as well as the information need of those people who try to answer them. Roughly, there were four main groups of people that contacted the help lines for information: professionals (teachers, prevention workers, but also GP’s, etc...), young people with questions about substances, parents and families (with general questions and with specific cases) and students.

¹ <http://www.elisad.uni-bremen.de>.

Based upon the assessment and subsequent discussions in the partnership, the following needs for the EELDA website were formulated:

- It should make reliable, unbiased and scientifically sound information on illicit drugs available to professionals and the interested general public. Access to scientific knowledge about drugs can be provided and improved as follows:
 - Scientific information is disclosed through critical selection and quality control, conducted on the basis of transparent protocols and methodologies;
 - Scientific information is disclosed for non-scientific professionals and the interested public by summarizing the evidence found in high-quality studies and research and presenting it in an accessible format;
- It should provide an answer to key-questions these groups may have. E.g. professionals in one country may sometimes convey different messages on the risks and effects of specific substances. From the drug profession there is a call to come to a greater consensus based on the latest scientific insights.
- It should contribute to the development of more effective interventions and policies.
- It should be transparent regarding the development process and methodologies followed.

For the initial development of the EELDA website, it was decided that a somewhat broad overview of basic information was to be created on three illicit substances and that during the maintenance phase this information would be updated and expanded with new aspects derived from recent frequently asked questions at the help lines and – possible – other information sources, developments and trends.

This approach is somewhat different than other sites that try to summarise evidence. The EELDA project could have limited itself to summarising available systematic reviews and placing these in a database, so that visitors of the site could search and retrieve such evidence. However, the project partners felt that more ought to be done. The site should also include promising new research for which no systematic reviews are yet

1.1 INTRODUCTION

At first sight, the development of a website containing scientific information – in this case for drugs and addiction – is not a revolutionary thing. In the field of drugs, dozens of informative websites exist today, so the question can be raised why there is a need for yet another one. At the same time, the fact that there are so many websites and resources available also creates a problem for those who are in need of objective, reliable and up-to-date information on drugs.

Scientific evidence is only as good until the next research-outcome that revokes its conclusions or sheds new light on specific phenomena. In order to be able to determine the quality of research and – inter alia – the quality of a website which includes summaries of such research, a transparent and systematic description of how information has been produced is indispensable. Visitors to a drug information website should feel they can rely on that its contents have been put together with the greatest possible care. One of the best ways to create such confidence is transparency, both regarding the processes and procedures followed to develop a website as such and the profile of its authors, as to the actual content development of – in this case – evidence-based drug information.

In this practical guide, the processes followed throughout the development process of the EELDA website are being described, taking into account the lessons learned, difficulties encountered and mistakes made.

1.2 FORMULATING NEEDS

As indicated above, a website containing evidence-based drug information should provide added value to already existing (web-based) information sources. Therefore it is essential to ask the question why a new site is needed (justification), what it should contain (contents), who it is made for (target group), how it can and should be produced with a high level of quality (development process) and how it can be kept up-to-date (maintenance). Finally, it is important to identify how such a site can be best brought under the attention of its target audiences.

available. Furthermore, visitors of the site and especially those who are not drug experts would probably not know how to deal with possible contradicting research or research uncertainties. Finally, the site should also indicate that if no conclusive evidence is available on a specific sub-aspect (e.g. the long-term psychological effect of cannabis use), what the available evidence does and does not say.

The three illicit substances that were chosen are: cannabis, cocaine and ecstasy. They were selected because they are among the most used illicit substances, especially among young people. There is a lot of confusion as to the effects and risks of the (recreational and frequent) use of cannabis, cocaine and ecstasy, but also regarding effective preventative interventions and effective treatment of problem use and dependence.

The main aspects covered on these substances are: general introduction, effects, risks, diagnosis, prevention and treatment. Each aspect includes several sub aspects.



1.3 IDENTIFYING TARGET GROUP

The fact that the EELDA information might be of relevance for a wide audience as described above, also posed a number of problems to the project partners. How much in-depth information should be offered and could be considered relevant. How could the scientific content be summarised best, what was the best way to present it and how would it be used.

One option was to create two parallel sites, one with scientific in-depth information for drug-experts and professionals who are not drug experts and another one with a popularised summary of that information for those in the general public who are interested in this type of information. The second option was to create a single website for both target groups.

Finally, it was decided that one website should target both groups. The argument for this is that drug experts usually want to retrieve and review the original studies that form the basis of evidence-based summaries. Professionals who are not drug experts will have difficulty to read high level scientific texts on this topic. The project partners concluded that the entrance level regarding drug-related information between professionals who are not drug experts and members of the general, interested public

is smaller than that between scientists and professionals. In this way information would not have to be duplicated.

The target group of the EELDA website was defined as follows:

- Drug experts
- Professionals in addiction care
- Medical professionals, e.g. general practitioners and nurses
- Professionals in social care, prevention and emergency staff
- Drug users and their direct family
- Professionals in other functions, e.g. police, teachers, policymakers
- Students of psychology, pharmacology and others in education
- General public (wanting to know more about drugs)

It is also important to note that the EELDA website is not a database of most effective programmes or interventions². It might contribute to the benchmarking of such programmes, but this is not a specific aim. Furthermore, the EELDA site is not meant to provide therapeutic advice to drug users and can never replace one-on-one contact with medical or psychological service providers.

² The Substance Abuse and Mental Health Services Administration (SAMHSA) in the US has developed a National Registry of Evidence-based Programmes and Practices (<http://nrepp.samhsa.gov>). NREPP is a searchable database of interventions for the prevention and treatment of mental and substance use disorders. SAMHSA has developed this resource to help people, agencies, and organizations implement programs and practices in their communities.

Project and resource planning

2

2.1 INTRODUCTION

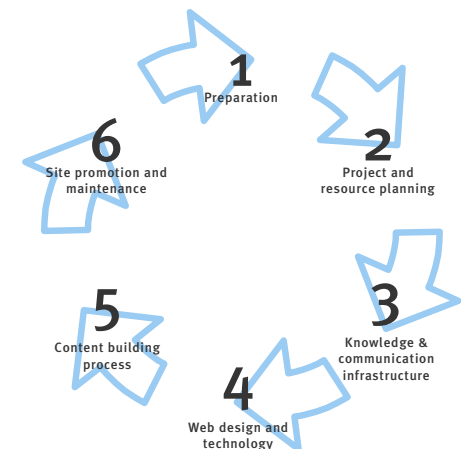
After identifying the main needs and target groups, a project plan had to be developed. Some of the main issues in this project plan concerned the estimation of the amount of work involved, the profiles and roles of the staff, the financial and other resources needed to do the work, the time required to complete the project and possible future resources to maintain the website and its contents in the future.

2.2 DRAFTING A PROJECT PLAN

The EELDA project was quite complex as it included project staff in three countries. As one of the main cornerstones of the project was to develop evidence-based content according to pre-described protocols and with great transparency, this posed important challenges to making available adequate communication tools to exchange information. From the perspective of time-management and the monitoring of staff outputs, simple but effective monitors were required to measure progress. This turned out to be one of the main challenges (and some times bottlenecks) in the project activities. In the next paragraphs the experiences with the EELDA project have been incorporated in the proposed actions and solutions.

In the development of EELDA, six development phases are considered elementary for the development of an evidence-based drug information website such as EELDA. The content development is a cyclic process. The six phases are reflected in Figure 1.

Figure 1 – development phases



Each of the six main phases in the project planning process required major decisions. In the preparation phase, as described above, the needs and target group of the project and its final outcome had to be identified. Furthermore, in the resource planning phase the working structure, staff involved and available resources had to be estimated. Each of these choices influenced the scope and width of the final product. The phase dealing with knowledge and communication infrastructure had an important challenge to link the daily work processes of the staff involved (in this case in three countries) with each other in the most efficient way. Some specific tools and communication processes were set up for this purpose. The web design and technology phase might be expected after the content building process. But the expected lay-out of the site as well as the technological ‘engine’ behind it has great impact on the way scientific authors do their work and write the contents and therefore it has to come before the content.

The most labour intensive phase was that of content building. As chapter five shows, this is a process within a process, with different stages and safeguards. The sixth phase is perhaps the most underestimated phase. Site promotion is a crucial element for the final success of a project like EELDA. There are many pitfalls and challenges. The website maintenance question is placed in this last part of the project development cycle, but it is in fact an issue that came up already during the preparation phase. After all, without maintenance a site such as EELDA is outdated with one or two years.

2.3 RESOURCE PLANNING

2.3.1 Human resources

The key resources required for the development of a site such as the EELDA website are human resources, finances and time. For the EELDA project, a multinational team with different backgrounds, working methods, languages and scientific experiences was brought together.

As the EELDA project was a relatively new exercise and the human resources available at the three partner organisations and the subcontractor were finite, attention had to be paid to a proper division of tasks and roles. For this purpose a profile was drawn up for key functions in the project, most of them related to one or more project development phases.

Some general requirements were formulated for all staff members. The people that were to be involved should:

- have adequate proficiency to communicate and – if relevant – write in English;
- be accustomed to use electronic communication tools (e-mail, international databases);
- be able to work independently;
- have at least a good general knowledge of the content matter they would be working with; and,
- last but not least being enthusiastic in sharing the project’s common goals.

Access to required IT technology (general and specific software) and email were essential for the daily working routines. The different levels of technological infrastructure had to be taken into account at the different working locations. But as it turned out during the project, availability of IT tools does not mean automatically that people actually use them.

The staff profiling was a key activity in the initiation phase of the project as the content building process identifies very clear tasks for different staff, the profiling could follow the process as well. In the project plan, the following key staff functions and roles were identified for the EELDA project (see also Table 2.1).

Table 2.1 – key staff functions EELDA project

Project coordinator	<ul style="list-style-type: none"> • Overall coordination: management of the project, main decision-making, planning and task division • Administration, finances, fundraising & final responsibility
Content coordinator	<ul style="list-style-type: none"> • Content coordination: the monitoring of the information production process (day-to-day cooperation between the different staff involved in content production)
Administrator/ webmaster	<ul style="list-style-type: none"> • Administrative support and website administration (access, passwords, etc.) • Deadline management • Web editing
Librarian/ information specialist	<ul style="list-style-type: none"> • Disclosing of available, published scientific research according to standardised and systematic database search strategies • Supporting authors in appraisal of literature
Scientific author	<ul style="list-style-type: none"> • Critical appraisal of retrieved scientific research with the help of critical appraisal tools for specific types of research • Selection of 'best-evidence' • Summarising of 'best evidence'
Scientific expert	<ul style="list-style-type: none"> • Critical appraisal of summaries
Editor/ journalist	<ul style="list-style-type: none"> • Editing of completed scientific texts into 'popularised' summaries
User panellist	<ul style="list-style-type: none"> • Appraisal of usability, accessibility, clarity and appropriateness of the produced content
Web technology experts	<ul style="list-style-type: none"> • Development of content building process • Web-design • Facility development, e.g. e-Community

Project coordinator

The project coordinator has the responsibility for the implementation, planning and quality assurance of the entire project. S/he takes care of the achievement of the overall aims and objectives of the project, financial and administrative management, staff management and allocation of resources

between partners, the contacting of review experts, the chairing of the project steering committee and the (coordination of) external contacts and fund raising. Initially, in the EELDA project, the project coordinator was also responsible for the coordination of the content building process. However, once the project was well underway, it was decided to appoint a content coordinator for this task.

Content coordinator

The content coordinator has the task to monitor and coordinate the scientific process and to deal with methodological and practical issues that emerge during the content building process. These issues include the selection of search strategies, the selection of databases, journals and other information sources but also the development of appraisal tools, in- and exclusion of study types (i.e. animal studies), etc..

Administrator/ webmaster

A crucial support function for the daily management and implementation of the project is that of the administrator/ web master. This team member is a spider in the web of project activities. S/he has the task to keep track of the different processes and provide overview to the project coordinator of what is going on. The administrator is also the day-to-day contact person to the different other functions and roles within the project, in particular vis-à-vis the website builder and technical staff, the translators and financial administrator. S/he manages access rights to the electronic working environment and processes the contents for the site through the content management system. As a consequence the administrator also has the role of webmaster. S/he is the focal point of all content for the website as the information has to be published in a uniform and organised way.

Librarians/ information specialists

The next crucial function in the content building process is that of librarians/ information experts. The librarians/ information experts in the EELDA project retrieved articles from indexed databases and library collections. But most librarians also had experience with complex database search strategies, filtering techniques and knowledge of (medical) database thesauri and search terms. Librarians/ information specialists for a project on evidence-based drug information need good knowledge of the drug field as they need to be aware of relevant search terms, synonyms, related

studies and study types and key resources in the field. An important and also difficult challenge in the EELDA project was the requirement that the prescribed protocols and procedures had to be followed, which turned out not always to be easy as these professionals have often developed their own working methods and routines. Librarians/ information specialists need to have access to relevant databases and be enabled to allocate serious time to search and retrieval activities of the project. In the EELDA project, four libraries were involved in the content building process.

Scientific authors

The core of the EELDA team consisted of the scientific authors. Where librarians/ information specialists are crucial for retrieval of relevant scientific literature, the scientific authors are the experts that appraise the evidence and its usefulness for answering questions about effectiveness and conclusiveness of interventions.

The selection of scientific authors is an essential step in the project. Authors must be experienced in critical appraisal of scientific literature and it is highly recommended that they have worked in the thematic areas they are asked to write summaries for. A good knowledge of terminology and some proven ability to summarise complex and sometimes inconclusive scientific literature without personal bias in a structured manner is preferred. In order to achieve consistency of content throughout the web site the authors must follow protocols and procedures established within the project. Furthermore, it is important that authors document their work process and decisions. Writing skills for the internet are recommended.

The EELDA project involved eight scientific authors, two of which were senior scientists in the field of prevention and treatment. The remaining authors were primarily young scientists with backgrounds in psychology and biology. It is recommendable to have staff build-up where on each main aspect (prevention, treatment, diagnosis, effects and risks) at least one senior scientific author is involved as a coach of less experienced staff. Senior scientific author needs to have an extensive overview of the thematic field concern and a good knowledge of relevant literature of the aspect/ substance combination targeted. S/he must be able to identify additional sources when necessary.

Scientific experts

Validating the work of scientific authors is an important safeguard for the quality of an evidence-based website like EELDA. In peer reviewed journals this is common practice. However, due to the dynamics of a website that is adjusted and updated on a regular basis, the expert review requires a good structure and continuity. As scientific authors have to focus on a variety of sub aspects, it is not always easy to self-review the contents from a distance. A peer review by scientific experts, preferably in different fields of drug information can provide new insights, relevant input on new research, but also detect possible bias regarding conclusions or methodological errors in the search process and in authored texts.

Experts that are contacted for a peer review should have extensive research experience. They might be selected on basis of their record of research publications in international scientific journals or from the partner's network. These experts must have a good overview of relevant literature and research.

In order for experts to review content, the information needs to be made available in a structured and accessible way, as this type of expert usually has limited time. The review should not be asked too early but only when authored texts are nearing their final stage. In that stage, there is a risk that texts have to be rewritten as a result of the peer review. But involving experts to comment on in-between drafts would ask too much of their time and involvement and would practically make them co-authors. For EELDA, the expert review was conducted at a late stage. This did result in the reviewing and rewriting much of the contents.

User panel

A website is only as useful as its visitor's think it is. Many scientific websites become obsolete because they have been designed from the traditional concept of scientific publishing, involving a lot of text and with little attention for usability and accessibility. It is important to take into account the experiences and perceptions of target audiences already during the project development process.

When an evidence-based website is being developed, the target group of potential users can be asked to examine its usefulness, its features, its



accessibility and perceived reliability, etc. A user panel does not evaluate the scientific content of a website, but is asked to try out the site, its navigation, its design, its search functions, the different links, etc. This includes reading texts from a user perspective with the aim to assess whether these understandable, written in clear language without too much expert terminology, if they provide information users would be looking for, etc. A user panel ideally consists of professionals and laymen. In the case of EELDA type websites the panel might include professionals from drug help lines, prevention and treatment centres. But also policy makers, teachers, families of drug users and possibly drug users (not necessarily drug dependent users) themselves.

Editor/ journalist

Another important staff function in the project is that of the editor/ journalist. S/he comes in almost at the end of the content building cycle, although it is useful to involve him/ her from the beginning. In the EELDA project, the involvement of an editor/ journalist came late. The project partners had planned to take care of the editing themselves since many of the staff involved had experience in editing scientific texts. The original build up of each webpage consisted of four parts: (1) a conclusion or key message, (2) the background of the topic, (3) in-depth scientific information and (4) references. In the end it turned out that texts still became too long and too scientific after all. It was decided to involve an editor/ journalist who had ample experience in editing and summarising scientific drug information for a broader audience.

The editing of summaries resulted in summary texts of approximately half a webpage per sub aspect. As a consequence, scientific authors could now focus more on the contents and the comprehensiveness of the scientific texts. The same time the editor/ journalist could focus on making the scientific texts ‘snappy’ and highlight relevant content in a format that was accessible for a broader audience. A benefit is also that future translation costs and re-translation costs for updates can be reduced by only translating the summarised, journalistically edited, easy-accessible and shorter abstracts, while keeping the main scientific article in the original language.

Translators

As in any project where translation services are required, it is of importance to find translators who have a good understanding of the original language they translate from as well as of the language they translate into. Preferably translators also have experience with the specific terminology used for the area of work. In the case of the EELDA website, translators were sought who had experience with texts on public health and/or drugs. Three companies were asked to translate a near final text from the site, so that their expertise could be examined.

Web technology experts

EELDA is a website containing evidence-based information. For the web-based infrastructure, one might consider to hire any website building company to take care of this part of the project development. However, for websites in the field of public health such as EELDA it is of importance that IT staff is involved that have a good understanding of the type of website that is to be developed and the possible problems that may occur throughout the building process. But that also have insight in how potential visitors try to access and use such a site. IT staff needs to have experience in building complex information databases and with designing content management systems (EELDA uses a CMS specially developed for the site). This type of websites might contain hundreds of pages of content that need to be changeable individually. For EELDA, a subcontracting company was hired that had ample experience in building databases and websites on evidence-based mental health topics. It also had staff with excellent understanding of literature search and review methods, of user requirements, of web technology and database management and of web-design taking into account accessibility and usability. The subcontractor played an important role in the thinking process on what type of website was required, what features were needed and how the content and technological activities could be implemented synchronically.

Financial administrator

As in any externally funded project a financial and project administrator was involved in the EELDA project to keep track of the resources spent on the activities, to provide management reports and input for the reports to the co-funding organisations of the project.



2.3.2 Budget

EELDA was an ambitious project. The project activities took place within four organisations in three countries. The project was partly funded by the European Commission, for the other part by the partners themselves. An important part of the daily work was done on line through an e-Community linked to the website. Even though the main and sub aspects related to each of the three substances covered in the database were identified in the beginning of the project, the total volume of text that was to be produced on the site was still unclear. And with that uncertainty, the required budget in terms of man-hours was also quite unclear and to a great extent based upon estimates.

The development costs for the EELDA site as described in this manual added up to approximately € 650.000. It is expected that once routine has been built up and once infrastructure has been established, the maintenance and expansion of an EELDA type website can be done at annual costs of app. € 100.000. The following categories of costs can be identified:

a) Human resource costs for the content building process

The human resource costs for the content building should not be underestimated. As the previous paragraph shows, many different experts and staff are involved to develop reliable and useful contents. Apart from actual 'content writing time', much time is required for the training of the staff involved, for communication and exchange, for selecting literature, reading articles, registering processes and procedures. Human resources might take up to 50% of the total budget.

b) Technology cost for the web infrastructure

The technology costs do include the human resource costs for technology officers, but as these are often part of a subcontracting agreement, they are a separate category. This category may add up to 30% of the total budget. These costs include:

- Purchasing/ developing a Content Management System
- Hosting costs for the website for the duration of the project
- Web design
- Web administration (from subcontractor side)
- Trainings for project staff

- Participation in project steering committee
- Adjustment costs (at least 20% of the subcontracting budget)

c) Communication costs

The expenses for communication depend on distance and available means in the collaborating structures. Communication through the internet (and an e-Community) can be cost-efficient if the collaborating partners have a well-function IT structure available. E-Community functionality can be built for app. € 10-15.000. Other communication costs may include video- or telephone conferences, which may costs between a couple of hundred to over a thousand euros. Communication through regular mail and courier services can also be costly, for example when packages of documents (and retrieved articles) need to be shipped to different partners.

d) Travel-and subsistence costs

Despite the possibilities of communicating through internet and email, including an e-Community, physical contact and exchange is essential for making projects like EELDA work. Project staff needs to know each other and exchange experiences, perhaps even work together on specific parts of the work (in EELDA, 'booster-weeks' were organised in which authors would work together, exchange and write). Furthermore, for a multi-lateral project, regular meetings of a project steering group are important for both strategic and management point of view. Furthermore, during these meetings, there is opportunity for providing trainings, which is also very important for new team members, as in multi-annual projects there staff changes are bound to happen.

e) Equipment and other IT costs

The expenditure on this type of costs depends on the facilities available within the collaborating organisations. Access to computers, access to high-speed internet, availability of relevant software (e.g. reference manager software for scientific articles, web design and web communication software) but also the availability of well-capacitated web-servers and email servers are important requirements. The availability and characteristics of the existing server infrastructure is an essential 'check' before starting the project. Once the website is up and running and nearing its completion, the subcontractor/ web builder will transfer technological management of the site to the project 'owner'. If server resources are not available, one might

end up with extremely slow, malfunctioning or inaccessible websites. It is possible to have a site hosted externally, but this generates structural costs. The type of server (e.g. SQL) may also influence the type of database that can be built and CMS software that can be used.

f) Document search and retrieval costs

An expense that can be easily overlooked is that of the document search and retrieval costs. As indicated above, it is important that librarians and authors have access to relevant international scientific databases. In the case of EELDA, access was required to databases such as MedLine, Toxline, Embase and PsychInfo. However, except for the popular version of MedLine (PubMed), access is not free. Embase might charge US\$ 10.000 per year for access or up to 100 US\$ per hour. Furthermore, often a price has to be paid for printed or downloadable copies of scientific articles, which may add up to € 20 per article, depending on the source and type of subscription a library has. In the UK, access to scientific databases has been made collectively available to public and non-profit organisations related to the National Health Service. In other countries, Universities usually offer collective access. It is important to budget this type of expense.

g) Translation costs

Translation costs represent a considerable part of the activity budget, especially if more than one language is concerned. It is important to determine in advance what exactly will be translated and what the estimated volume is going to be. Sometimes it may be more economic to hire translators in the countries of the target-languages.

h) Promotional costs

A scientific website usually does not promote itself automatically, especially when it is just opened to visitors. Therefore some budget needs to be reserved for promotional costs. This may include registration, participation and presentation costs at relevant international conferences (including conference stand), where the final product can be presented, but also targeted advertisements in professionals' journals, posters for key target groups. A lot can be done in terms of free publicity too.

i) Training costs

The training costs for staff involved in an EELDA style website can be limited and often combined with other activities within the project. However, some expenses need to be budgeted for travel and accommodation, materials, the services of specialised trainers (i.e. on web-based writing skills), but also for the development of training modules for an e-Community.

2.3.3 Planning and time management

One of the most difficult elements regarding the management of the project concerned the management of time. In the end, the EELDA project took more than three years to complete, although the first year was mainly lost due to a difficult start because a key partner discontinued its cooperation due to national budget cuts, but also due to the fact that the main funder (EC) took 15 months to decide and prepare a contract. Table 2.2 reflects a rough overview of the EELDA project planning.

	Period	Activities done
1	Month 1-3	<ul style="list-style-type: none"> Project start-up Consultancy visits prproject partners
2	Month 4-7	<ul style="list-style-type: none"> Steering committee meeting/ start up Choice of substances (Cannabis/ Cocaine/ XTC) Resolving partner replacement
3	Month 8-13	<ul style="list-style-type: none"> Steering committee meeting Initial categorisation of aspects and sub aspects for the chosen substances/ thematic breakdown Initial design of EELDA website Training course for steering group, authors & librarians Pilot project: literature searches, retrieval and appraisal Development literature screening protocols Development critical appraisal tools
4	Month 14-18	<ul style="list-style-type: none"> Steering group meeting & process standardisation meeting Literature searches and screening (first substance: cannabis) Literature search and document retrieval First critical appraisals of evidence



5	Month 19-23	<ul style="list-style-type: none">• Steering group meeting• Training on 'Writing for the web'• Literature search and document retrieval (ongoing)• Critical appraisal evidence (ongoing)• Authoring evidence-based summaries• Authors' writing and exchange weeks (booster session)
6	Month 24-28	<ul style="list-style-type: none">• Literature search and document retrieval (ongoing)• Critical appraisal evidence (ongoing)• Authoring evidence-based summaries (ongoing)• Steering group meeting• Authors' writing and exchange weeks (booster session)• Start manual development• Presentation of methodology in international conferences• Web editing
7	Month 29-35	<ul style="list-style-type: none">• Evaluation meeting steering group• Corrections & translation• Writing of manual• Development of info cards, poster and sizzlers for promotion of the site• Website redesign, functionalities added (reference manager, newsletter, content review module, improved CMS)
9	Month 35-39	<ul style="list-style-type: none">• Expert review of authored content à in-house experts• Website usability and accessibility review à drug helpline staff• Re-launch of searches and revised critical appraisal
10	Month 40-48	<ul style="list-style-type: none">• Rewriting of original authored texts• Summarising of contents, especially Cannabis and Cocaine• Follow up planning, promotional activities and presentations• Opening of website• Start of regular revision of contents (prevention & treatment)

One main challenge in the planning of the EELDA project concerned the correct estimation of the work that had to be done. Depending on the main and sub aspect, librarians retrieved very different quantities of – at first sight – relevant scientific literature. In the field of effects and risks, a great abundance of studies is available, while for treatment and prevention the number of relevant (meta-) studies is more limited. The search and appraisal process requires a good system of time management and job-allocation for the staff involved.

Knowledge and communication infrastructure

3

3.1 KNOWLEDGE INFRASTRUCTURE AND TRAINING

The EELDA website could not have been developed by just any organisation in the field of (public) health. Specific knowledge about the drug field is required, as well as its interaction with the field of mental health and that of toxicology studies. Key expertise in project staff needs to reflect the different aspects (effects, risks, diagnosis, treatment, prevention) covered by the contents of the site. Furthermore, the scientific support structure (library services, access to scientific databases) needs to be well established. For the EELDA project, the necessary databases were matched with the resources available through the four libraries. Furthermore, search techniques were shared (e.g. search filters). Ideally, the scientific authors also have access to a broad network of external experts and groups of professionals to assess and evaluate the outcomes of the scientific activities.

Training has a crucial role in developing the knowledge infrastructure. In geographically dispersed collaboration projects such as EELDA, much attention needs to be given to adjustment and exchange of working methods and practices. The EELDA project, with key tasks divided over the different project partners, required some level of unification in working methods. At the beginning of the content building process, a 2-day training session was organised for all staff involved in the project with the objectives to:

- "Put a face on a name" and ensure that the people involved in the project get to know each other.
- Create a common sense of understanding of the projects' key working methods and requirements
- Promote the importance of quality assurance in every step of the project by explaining and analysing the methodology
- Exchange experiences and approaches with the purpose of finding common standards
- Reflect on the project's ambitions and final objectives and outputs
- Identifying roles and tasks of the staff involved
- Identify important high quality databases on drugs
- Learn how to work together in an electronic environment (E-Community)

The training included presentations on Evidence Based Medicine and a simulation of systematic searching in databases (search strategies,

precision and recall, reducing uncertainty and coincidence factor) as well as on the selection and appraisal of evidence (appraisal tools adapted to substance-aspect combinations, types and levels of evidence).

A part of the EELDA staff had prior experience in retrieving and summarising evidence-based information. In those cases where a broader introduction is needed for relatively new staff, topics may be added to the training, including:

- Identification of key topical areas for a website on drugs, including the identification of local trends and/or cultural differences in patterns of drug use
- Input on how to adapt Evidence-based Medicine (EBM) to the drug field: its meaning, difficulties, approaches
- Determining research types per substance-aspect combination that provides important and relevant information
- Identification and appraisal of important grey literature; methods of use
- Development of EB working procedures, quality control, logistics management, publishing and maintenance of information
- Writing evidence-based summaries for the Internet

Pilot project

After the initial training, the project staff (especially the librarians and authors) were asked to run three different searches/ appraisal routines. The purpose of this pilot was to reveal differences in approach, to show that different people can obtain different outcomes in a search process for the same search question, this with the aim to 'test' and adjust the prescribed procedures and protocols and collaboration practice. The pilot showed that 2 out of three libraries obtained very different search results, sometimes 'missing' key scientific publications. Furthermore, the final selection of literature that was considered relevant showed big differences between authors as well. On the basis of the pilot, the protocols and procedures were adjusted and the appraisal tools further developed (a specific tool for each type of aspect). One important conclusion was also that librarians and authors need to communicate often throughout the search and document retrieval procedure.

An important part of building the knowledge infrastructure concerns the continuous attention for evaluation and learning. The EELDA project introduced existing and new working methods into a new working area. These working methods require fine tuning and adjustment. Furthermore, by exchanging experiences, the key staff can learn from each others achievements and mistakes, which benefit the activities as a whole.

3.2 COMMUNICATION INFRASTRUCTURE

Apart from the knowledge base that is required for a project like EELDA, the communication infrastructure is also very important. In order to facilitate ongoing communication between project staff in the three countries, a communication plan was developed and supporting tools were introduced. The communication plan included a description of:

- Who should have access to what type of information
- Who should communicate with who at what stage
- When to communicate: desired frequency of communication
- How to communicate: methods of communication
- What to save: information, routines, decisions and choices made
- What progress to monitor: feedback routines and progress worksheets

General project meetings were organised every six months by one of the partner organisations. These meetings played an important role in creating a unified team and in re-iterating the project goals. During each meeting a short process evaluation was conducted, identifying if tasks had to be reassigned or approached in a different way.

In addition to the meetings, regular telephone conferences were organised to provide an update to the different project staff (and local project managers) as well as to assess progress and identify problems.

A special role within the EELDA project was reserved for the web based e-Community (see box 3.1). The e-Community is a project 'intranet' website, which was created with the intention to increase the efficiency of information exchange. The e-Community allowed the project staff to communicate with each other by posting messages in topical forum areas



(see Figure 3.1). This proved to be a successful communication tool between authors and librarians. The e-Community also included all project related documentation such as the project plan but also literature search forms, appraisal tools and methodological documents but also training materials and presentations needed for events. Authors were asked to submit here their search forms and these were further processed by the librarians.

A general subscription mechanism was put in place; every participant was alerted by email whenever a new thread/ topic were created. The forum also played an important role in efficiently exchanging contradictory arguments. However, in the beginning, many of the users seemed to be reticent towards using this new communication tool. Probably a more high profile launch of this instrument would have created more enthusiasm in the user community, resulting in an improved usage.

Box 3.1 – functions of the e-Community

- Discussion and exchange on work processes and procedures
- Discussing problems and inconsistencies
- Monitoring and reporting progress through progress worksheets
- Storing information, procedures and routines (search forms, search routines, appraisal tools, up- and downloads, presentations, etc.)
- Archiving articles and evidence

On project level, different individuals and functions require different types of information:

- The project manager needs overview of all processes and the time investments they take to plan human and financial resources, involve experts, panellists, editors and translators.
- The content manager needs overview of progress in the content building process, text production and time utilisation to identify bottlenecks and methodological issues so that these can be solved.
- The administrator/ webmaster needs information on progress to plan and adjust workloads/ jobs between project staff and to plan day-to-day publication, editing and translation of content.
- The librarians need info on upcoming search requests and need to provide feedback on in which stage ongoing searches are.
- The authors need to know whether search requests are being processed and what the results of ongoing searches have been.

By the end of the project implementation period, additional functionalities have been added to the EELDA website with the aim to increase its user-friendliness, both regarding visitors to the site as well as the people involved in developing and maintaining the site and its contents. The following key functionalities were added:

'Jobs' allocation module

This module provides project staff with an overview of existing 'jobs': the tasks that need to be conducted. These include the 'jobs' each individual is involved in, the jobs that require immediate action of the staff member concerned and jobs which this staff member creates for other staff. The 'job' routines can be prescribed by the project manager, so that everyone that needs to be involved after the launch of a job is automatically informed and alerted. A job is closed when all staff involved has finalised their task. This function helps the project manager and administrator/ webmaster to a great extent to monitor progress and to identify obstacles and delays.

Expert review module

In the EELDA website, a 'backdoor' has been created through which scientific experts can review texts online through and email alerted system. The authors receive the reviewed content back and can adopt or reject suggestions (similar to track-changes in Word). The system also allows the webmaster to track the status of the work, as s/he can see what 'jobs' are still open and need action.

Reference management functionality

As the content of the EELDA site includes numerous links to scientific literature, it was necessary that an easy updatable and automatic reference management system was introduced. In the final CMS, this reference management function does not only allow the upload of data files containing literature references, it allows for efficient management of references as these only have to be entered once and can be referred to from any text.

Future additions – e-Learning

The future plans for the EELDA site include a gradual expansion of the network of scientists working on the site, as well as the introduction of educational facilities for specific groups of experts. One idea to facilitate



these plans was to develop an e-Learning facility for the EELDA website. Such a facility might enable people that have basic skills in working on evidence-based drug information to discuss and exchange experiences. Participants to the e-Learning facility would be able to share experiences, problems, methodologies and approaches with their colleagues from other countries, by posting requests and queries. Resources would be developed and separate discussion groups initiated on the specific topics, including for example:

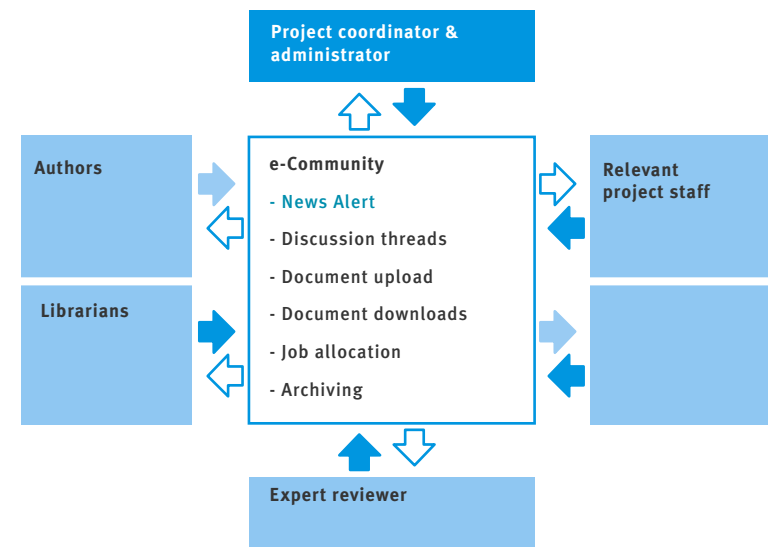
- Systematic searching for literature (e.g. (peer reviewed) journals and grey literature)
- Selection of relevant literature
- Appraisal of evidence
- Writing for the web
- Identification of relevant national or local information
- Co-ordination of development of EB databases and websites
- Website and content maintenance
- Section on new trends and (unpublished) literature



Figure 3.1 – the EELDA e-Community

Status	Type	Author	Posts	Last reply
			5	10 December 2004, 17:24 Posted by andre martin [View]
			11	29 November 2004, 16:23 Posted by msource [View]
			11	26 January 2005, 09:44 Posted by vitor [View]
			7	09 July 2004, 09:50 Posted by martin [View]
			7	11 November 2004, 11:02 Posted by mhh [View]
			7	10 March 2004, 11:08 Posted by douglas [View]
				27 February 2004

Figure 3.2 – e-Community as communication centre



Web design and technology



4

4.1 INTRODUCTION

The ambition of the EELDA project was to develop a leading resource website for evidence-based information on drugs and drug addiction for both professionals and the general public. In order to gain such a position, some issues are crucial. The site must be up-to-date, reliable, accessible and usable. And finally, the technology must support the visitors operations and not hinder these. The first will be discussed in the next chapters. The issue of reliability is also important from a web design point of view.

4.2 WEB DESIGN

4.2.1 Usability

The usability of a website encompasses a lot of different elements. It depends on a range of factors. First of all, specific choices need to be made in order to achieve an optimal browsing experience. The structure of the site should be kept as simple as possible and the different sections should be structured in a similar way.

Before the EELDA site was designed, some intensive thinking was done regarding the point of entry. A key question was whether the site should be structured according to the different types of substances (cannabis, cocaine and ecstasy) or according to the main aspects covered per substance (effects, risks, diagnosis, treatment, prevention). Furthermore, attention was paid to the menu structure and the number of levels, the cross links between pages and links to external websites.

For the EELDA site it was decided to structure the site per substance. The reason was that it was assumed that most non-scientists, e.g. professionals and members of the general public do not specifically look for all available drug treatments, but e.g. for treatment options for cocaine addiction or problematic cannabis use. Furthermore, in the EELDA site, the number of levels has been limited to four at most (substance – main aspect – summarised sub aspect – detailed information).

Another important issue for good web design concerns the browsing structure and 'picture' of the site. Authors like Nielsen (1999) present a large number of examples of web designs and discuss the main advantages and disadvantages of different designs. Many websites show an abundance

of navigation tools and menu structures, making it sometimes difficult for visitors to browse through a site (examples include endless ‘loops’ between pages).

Besides an uncomplicated browsing structure it is important to provide a good search function. If visitors are not able to find the answers to their initial questions within a few seconds they will go elsewhere.

A lot of attention has been given to the design and usability of the EELDA site. Standard functionalities and usability enhancements are provided for each information item throughout the site:

- The site is designed with a consistent and clear approach that uses CSS (cascading style sheets)
- Each article has also a printer-friendly version
- The visitors should have the option to download articles, in original format or as protected PDF files
- The website should be well displayed in all screen resolutions that could be used by the target groups
- The visitors can provide feedback function. A standard feedback form can be filled in.

Several other functionalities have been investigated as well. Not all of these options have been included:

- User evaluation tools. These may include short web-based questionnaires for visitors of the site, focusing on different aspects, including contents and functionality.
- Email alerts when new content is placed could be provided to registered users subscribed for this option. Alternatively targeted newsletters could be published through the same registration mechanism. Currently on the EELDA site there is no requirement for any form of user registration.
- Many websites include discussion forums. A discussion forum can attract more visitors to the site. However, there are downsides to such functionality. First, it is expensive to structure and moderate a discussion forum. The legal implications in providing this option to a multi-lingual user community can be far reaching and can vary largely by country. Last, user registration is implicitly part of a discussion forum and that would conflict with the previously made

choice for a low level entry website.

- In EELDA, no personalisation of pages has been introduced. General internet surveys show that personalisation of pages is expensive and remains unused. Furthermore, the visitor is not encouraged to fully make use of the menu structure already provided.
- As the information on the website is subject to frequent updates it should not be too easy to link to specific and original articles. Another reason for this choice is that the aim is that visitors come back to the site and review the updated content and not just parts of it.

4.2.2 Accessibility

A second, sometimes underestimated condition for successful websites concerns the issue of accessibility. Two fields should be addressed when addressing website accessibility.

First the envisaged target groups should be able to easily reach the site. A simple URL (www.eelda.org) and search engine optimisation techniques are essential steps to be taken. Relevant, well chosen meta-data tags³ should be available and search engine crawlers and spiders should be triggered. A consistent search engine optimisation policy should be applied throughout the site. Each article should also include content specific meta-tags. The search engine optimisation policy should be well documented within the project.

Second, the technical design of the site should comply with basic accessibility best practices. It should comply with international standards such as those developed by the Web Accessibility Initiative (www.w3c.org/wai).

The EELDA site is designed for enhanced accessibility: the site should be compliant with speech synthesizer software (for visually disabled persons), the text size should be changeable, and the page lay-out should optimally adapt to different screen resolutions.

³ These are labels attached to web pages in a site, so that the key words in these pages can be screened and identified by (external) search engines such as Google and Altavista.



In order to make sure the site is easily available in places without a high speed network connection the content should be carefully screened in terms of bandwidth usage. No exotic technologies (such as complex frames, flash animations, applets, ActiveX controls, or client-side scripts) have been used, in order to ensure compatibility with the various browsers used by the heterogeneous public. As mentioned before, for the EELDA project, the choice was made not to register visitors, as this may limit accessibility.

4.2.3 Testing of the site

Informal feedback about the site was and is received on ad hoc basis from relevant workshop events and conferences. Furthermore, feedback may be gathered from the web site itself via a feedback page and e-Community, where involved staff and experts can reflect on the site.

If appropriate, it is possible to set up more elaborate usability testing to ascertain how well the EELDA site works for key groups of users. There are a number of ways that this kind of testing can take place, these include:

- Basic usability testing: ask a representative group of users to try and find answers to specific questions on the EELDA site and evaluate how well they do. This type of testing need not be carried out with that many people to produce useful results. The user panel in the content building process is one example of this type of assessment.
- Lab-based usability testing: similar to the above test but study the users in a lab environment with video technology or eye tracking software. This is a rather sophisticated type of testing.
- User satisfaction (panel review)
- Usability testing

4.3 KEY DECISIONS REGARDING TECHNOLOGY AND CONTENTS

As indicated in the previous chapters, the technology required for the EELDA site was an issue that required attention from the beginning. The size and characteristics of the target audiences, the type of content, the choices regarding the point-of-entry, the technical facilities and options for both users and staff... All these issues have an impact for the choice of technology and software needed. The project partners had decided in the

project application phase already, that a specialised subcontractor was needed which could advice and provide the technology and software that was required.

As a result, the EELDA site has been designed, maintained and hosted by the independent contractor Minervation Ltd. A hosting agreement has been agreed between the project leader and the subcontractor.

The content management system (CMS) used to deliver the EELDA web site has also been designed and built by Minervation Ltd. This system allows secure access to the back-end of the site so that anyone with access to the Internet can edit web site content when authorised to do so. System administrator users can also add new pages and sections to the site, administer web site users and administer the e-Community. Making use of a flexible CMS has meant that EELDA project participants have been able to work independently from each other on their own discrete areas of the project. This was a key deliverable of the project.

The decision to use a tailored CMS has meant that the project is in an excellent position to develop in a variety of new directions. The CMS could be developed in the future to include project administration features to further improve the management of authors and reviewers. It could also deliver a variety of alternative formats for content (e.g. PDA), should the functional use of the site require such in the future.

The design and layout of the EELDA site has been implemented in a way which meets accessibility and usability guidelines. The clear and consistent design makes minimal use of graphical elements, whilst retaining a clean and aesthetically pleasing feel.

The site architecture also follows a consistent approach by dividing the navigation system into different sections for each substance (e.g. cannabis, cocaine, ecstasy) and consistent subsections (e.g. introduction, effects, risks, diagnosis, prevention, treatment). Organising content in this way minimises the cognitive overhead of the site and makes it easier for new users to quickly become familiar and comfortable with the site structure.

The content building process



5

5.1 ABOUT EVIDENCE-BASED RESEARCH

In recent years, the term ‘evidence-based’ has gained great popularity in all areas of the drug field. For many people, the fact that interventions or policies are evidence-based creates a certain sense of reliability. It suggests that there is a sound scientific base underneath the intervention or policy. However, the term ‘evidence-based’ does not say so much in itself. Primarily it means that an intervention or policy is based upon the ‘best available evidence’.

If ‘best available’ in practice means that there is little evidence available, the intervention or policy is still evidence-based. But it may or may not be better or more effective than other interventions or policies because evidence-based does not automatically implies that a policy or intervention is effective. Effectiveness says something about the (intended) outcome of an intervention or policy, while evidence-based might simply mean that it has been researched.

The call for evidence-based policies and interventions originates from Medical Sciences. Evidence-based Medicine (EBM) is *‘the conscientious, explicit and judicious use of current best evidence in making decisions on individual patients’*. This means *‘integrating individual clinical expertise with the best available evidence from systematic research’*⁴.

Evidence-Based Medicine (EBM) can be presented as a five step model⁵:

1. Asking answerable clinical questions
2. Searching for the evidence
3. Critically appraising the evidence for its validity and relevance
4. Making a decision, by integrating the evidence with clinical expertise and the patient’s values
5. Evaluating the decision

It would go beyond the purpose of this practical guide to explore in-depth all the specific characteristics and processes in Evidence Based Medicine. The drug demand reduction field comprises a mixture of medical (clinical) research and social science research. Drug demand reduction

⁴ Heneghan, C. & D. Badenoch [2006], p. 2.

⁵ Ibid, p. 2.

is a part of public health policy. It includes elements such as prevention, treatment, rehabilitation but also substance-related risk assessment (incl. toxicology).

For the EELDA project, the above mentioned five-step model has been translated to the non-clinical practice of social science research. This translation also surfaces some difficulties regarding the application of evidence-based approaches in the drug field.

There is an ongoing debate about the best methodology in determining effectiveness in public health. Traditionally, medical science uses stricter rules for experimental research and the 'gold' research standard is a so called randomised controlled trial (RCT). However, in public health issues such as drug demand reduction, a research design as applied in an RCT is often difficult or impossible.

First of all, many of the influencing factors are often unknown or can not be controlled within the experiment. Secondly, due to influence of other policies (e.g. international drug laws/ law enforcement), it is not always possible to conduct a study without restrictions. Thirdly, some studies are ethically unacceptable. For example, if a specific medication exists that neutralises the effect of drug overdose, it would not be ethical to conduct an experiment in which one would randomly withhold this potential lifesaving intervention from one overdosing drug user compared to another.

From a strict scientific sense, alternative designs to RCT's are not always considered optimal to prove effectiveness. The methodological debate on the study design suitable to produce evidence of effectiveness in public health currently remains unsolved.

One major difference between the evidence-screening process conducted for websites such as EELDA and Evidence Based Medicine conducted by medical doctors, concerns the fact that the EELDA project aims to obtain an overview of what works and what does not in drug demand reduction, while in clinical practice specific medical interventions may be examined closely, based upon specific conditions of patients.

Finally, when it comes using evidence-based information for policy purposes, it is important to reiterate a number of important principles:

- The fact that no research evidence exists for specific types of interventions does not mean that these interventions do not work. We simply don't know and if the lack of evidence would result in a policy decision not to implement such interventions, science in drug demand reduction would come to a halt. The key phrase here is trial-and-error. We develop, implement, evaluate and adjust/decide on the basis of information gathered in the process.
- On the other hand, even the most effective intervention – placed against the background of a specific economic or medical perspective or political reality – may not always be politically acceptable or feasible. In those situations, a second best solution may suffice ⁶.

The EELDA website presents in-depth evidence-based information on three illicit drugs: cannabis, cocaine and ecstasy. Where available, it also presents information on the effectiveness of interventions. In general most evidence was found on the effects and risks of these substances. Evidence on effective treatment was not found for all substances, simply because there are not yet too many evaluated treatments available for e.g. the problematic use of ecstasy. In the field of prevention, many case controlled studies exist, but the number of RCT's is limited. Meta-analyses, providing a complete overview of the available scientific literature on specific areas of prevention, are available to a limited extent.

In order to determine the availability, relevance and usefulness of scientific evidence, a number of important steps have to be followed. In Figure 5.1, the content building cycle for the EELDA website is presented. This elaborated model is part of the five-step approach as presented above, but integrates the evidence selection and appraisal process with the web publishing process. In the next paragraphs the different stages are being described.

⁶ Borst-Eiler, E. [2001]. 'Medicine and Politics: the many shades of evidence'. Lecture for the 9th Cochrane Colloquium, Lyon, France.



5.2 FORMULATION OF SEARCH QUESTION

The EELDA project aims to identify the best available, high quality scientific evidence on key aspects related to the use of cannabis, cocaine and ecstasy. Such evidence does not emerge by itself. It has to be searched for and only the most relevant studies have to be retrieved. There are a number of relevant international databases that contain scientific articles from (drug-related) research from all over the world. In addition, there are many relevant printed scientific journals that also publish highly relevant articles.

In order to find the most relevant studies, one has to formulate specific and targeted search questions that guide the librarians/ information specialists in such a way that they can translate the search question into the most suitable search strategy. For the EELDA project, the question formulation was tested in the pilot phase. Use was made of the PICO model (see box 5.1), which provides a systematic approach to defining a clear and searchable question.

Box 5.1 - PICO model

Questions should be clearly formulated and it should be possible to split them into searchable units:

- The **P**atient, population or problem area;
- The **I**ntervention, test, treatment, prognostic factor or causative agent;
- The **C**omparison intervention against which it is compared (if appropriate);
- The **O**utcome, target disorder or behaviour being studied.

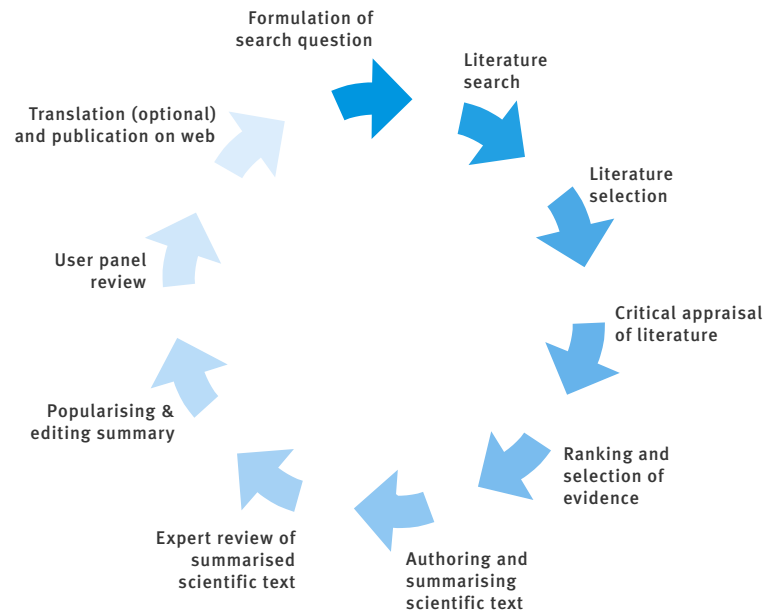
Source: Heneghan and Badenoch [2006]

For the literature searches, a standard form was created for the question formulation. The PICO-model based template included the following elements:

- The aspect of the specific substance to be researched and its positioning in the website structure;
- The question that needed to be answered. This question was not too detailed as this might complicate the searching process for the librarians. The form included possible synonyms and alternative phrases that should also be included in the search process.
- An exhaustive list of the databases to be researched (Medline/ Pubmed, PsychINFO, Toxline, EMBASE, CINAHL, Cochrane)

- Identification of which author asked the question
- Cross references that needed to be checked

Figure 5.1 – EELDA content building cycle



For the purpose of documentation and transparency, procedures and decision making protocols have been laid down in writing, with the aim to ensure their application by all relevant project staff. The search questions have been saved as well as the search strings for each question.

5.3 LITERATURE SEARCHING

The effective searching of scientific literature within international databases is a task that requires good overview of searching terminologies, information on how databases are built up and experience with searching processes.

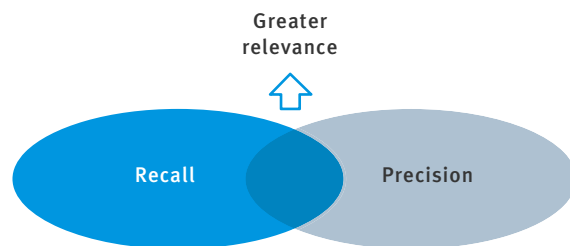
In the EELDA project, four different libraries and eight librarians/ information specialists participated in parts of the search activities. Due to different backgrounds of these experts, there were different approaches to literature searches which called for efforts to harmonise as much as

possible. A standard, project-wide approach to literature searching was developed as much as possible. The project partners acknowledged that each method had its own strengths; the aim was to adopt the best elements of each approach into the EELDA literature searching approach. This was a complex task and not always easy to perform.

Each international scientific database has its own thesaurus and search terminology (e.g. MedLine has Medical Search Headings (MeSH)). The search requests had to be adapted to the specific databases. The general rule that applied was that searches were conducted from wide to narrow (e.g. a search request on the risks of cannabis and pregnancy among teenage girls was broken down into 4 or more separate search strings). By doing so, in each step *precision* would increase while *recall* (the steps towards the final outcome) would be safeguarded, thus ending in a more or less relevant selection of literature (see Figure 5.2). By doing so, the risk of bias was reduced as each step was repeatable.

Furthermore, where possible, the literature searches addressed primary research (case studies, RCT's) first. This was done in the context of checking whether secondary research (evidence summaries, systematic reviews) addressed the right type of studies or because secondary research was absent, incomplete or out of date.

Figure 5.2 – recall and precision



5.3.1 Using search filters

As the EELDA website would contain a lot of sub aspects (e.g. physical effects, psychological risks), which were partly comparable for each of the three substances and per key aspect (effects, risks) and some of the libraries involved in the searching had gained positive experiences with search filters (predefined search strings in which terms may be replaced),

such filters were developed to target the right type of study to suit a particular question. The librarians could combine these filters with their subject searches to identify the studies which are most likely to give a reliable answer. In practice, the search filters did not fulfil their promise. Many irrelevant studies were retrieved with these filters. Furthermore, despite the standardised search procedures, it was still necessary for librarians and authors to consult each other on a regular basis to fine tune the search process and to cross reference existing studies for tertiary references.

Based on the search questions, a systematic, transparent and reproducible literature search was conducted following standardised protocols as much as possible. However, the results were not always satisfactory. For some aspects hundreds of literature references were found that needed to be examined, in many cases without abstract and in some cases referenced in a wrong way (the database abstract did not cover the content of the article or the category it is archived under).

Through the process of searching, adjusting and consultation between librarian and authors, the relevance of the identified literature improved. At the end of a search process, the identified literature was physically retrieved from the databases, libraries and other sources and transferred to the authors.

5.3.2 Managing the search process

As the work of the authors depends to a great extent on the input provided by the involved librarians, it is important they have adequate time and resources to implement and refine searches. It has proven to be difficult to correctly estimate the number of articles returned in the first instance by literature searches.

Furthermore, in the EELDA project after a couple of months of implementation, it turned out that for authors, librarians and the project coordinator and administrator it was difficult to keep track of progress in the dozens of literature searches that were going on at the same time. Furthermore, authors received files which contained some doublings in literature reference files. As a result, an 'informal' coordinating librarian was identified who had the task to collect all searches on a specific search

question from all librarians involved, merge the results into one file, delete the double entries and submit to the authors concerned one comprehensive file, which s/he could select literature from.

Furthermore, the coordinating librarian would play a key role in monitoring the status of the various searches, dispatch new searches, manage work load of the other librarians, returning results. At the end of the project it was concluded that the role and position of the coordinating librarian should have been made more explicit and that the process of creating overview should receive a lot of attention and structuring (including clear division of tasks and feedback loops, such as on the number search requests from authors; how they are archived and their status, e.g.: announced, open, closed, reopened).

5.4 LITERATURE SELECTION

The literature that was retrieved in the search process was in some cases not straightforward. In searches where many case studies and other primary sources were found, the search routine was narrowed down to capture studies that represented a higher level of evidence. In some cases authors indicated such study types in advance (e.g. for prevention, mainly systematic reviews and RCT's were the focus of the searches). When studies were scarce, the searches were widened to studies of lower quality.

Study types that were targeted in the searches included:

1. **Case-control studies:** people with the outcome of interest (cases) are matched with a similar group without it (controls) to see if there are any differences in their exposure to a causative factor. These studies are often retrospective.
2. **Cohort studies:** people who have been exposed to the intervention or causative factor are matched with a similar group who have not been exposed to it and followed forwards to see if they develop the outcome.

3. **Cross-sectional surveys:** a defined group of people are assessed at a given point in time to see if they have the condition of interest.
4. **Randomised controlled trials:** people with the condition of interest are randomly assigned to receive either the intervention of interest or a control regimen, then followed forwards to see if they develop the outcome of interest.

The types of research that were expected to provide the best answers to the questions in the EELDA project are shown in the table 5.1.

Aspect/ type	Level 1	Level 2	Level 3
Pharmacology	RCT		Validated recommendations
Toxicology	RCT		Validated recommendations
Prevalence	Cohort study	Retrospective cohort study	Cross-sectional survey
Diagnosis	Cohort study with blind, independent comparison with a gold standard		Retrospective, or non-consecutive Level 1 study
Prognosis	Cohort study	Retrospective cohort study	Case-series
Harm/Aetiology	RCT*	Cohort study*	Case control study
Prevention	RCT	Cohort study	Case control study
Treatment	RCT	Cohort study	Case control study

* Questions on Harm are most likely to be addressed by case-control studies

Whenever systematic reviews were available for a specific section, these were included in the selection, as these provide an overview and assessment of all available literature for that section.



5.5 CRITICAL APPRAISAL OF LITERATURE

Once scientific literature has been identified and retrieved, the actual work of assessing its quality and relevance is only beginning. The articles that have passed through a solid literature screening and selection process should ideally be studies that have the right focus, are relevant to the search question and comply – formally – with the requirements regarding study design.

Whether the retrieved literature actually provides answer to the search question, if it is of high quality and – most importantly – if its outcomes are reliable, is to be determined in the critical appraisal process.

Critical appraisal is a special art in itself. It requires a high degree of preciseness and objectivity. In the scientific (medical) society, a number of important scientific collaborative networks exist that aim to improve the quality of research and therefore also the quality of decisions taken on the basis of scientific evidence. These networks do so by critically appraising important literature. One of these networks is called ‘The Cochrane Collaboration’ (see box 5.2). For the field of sociological and behavioural studies, a similar structure has been set up, referred to as ‘The Campbell Collaboration’. This network tries to find new research methodologies in the field of social and behavioural sciences, with the aim to improve the applicability of strict research methods and increase the reliability of study outcomes in this field.

Box 5.2 - Cochrane collaboration

The Cochrane Collaboration is an international, not-for-profit organization that aims to help people make well-informed decisions about healthcare by preparing, maintaining and promoting the accessibility of systematic reviews of the effects of health care interventions. To accomplish these goals, all members of the international Collaboration follow a rigorous protocol that ensures Cochrane reviews are unbiased, valid, thorough and reliable.

Guiding Principles

The Cochrane Collaboration’s work is based on ten key principles:

1. Collaboration, by internally and externally fostering good communications, open decision-making and teamwork.
2. Building on the enthusiasm of individuals, by involving and supporting people of different skills and backgrounds.
3. Avoiding duplication, by good management and co-ordination to maximize economy of effort.
4. Minimizing bias, through a variety of approaches such as scientific rigour, ensuring broad participation, and avoiding conflicts of interest.
5. Keeping up to date, by a commitment to ensure that Cochrane Reviews are maintained through identification and incorporation of new evidence.
6. Striving for relevance, by promoting the assessment of health care interventions using outcomes that matter to people making choices in health care.
7. Promoting access, by wide dissemination of the outputs of the Collaboration, taking advantage of strategic alliances, and by promoting appropriate prices, content and media to meet the needs of users worldwide.
8. Ensuring quality, by being open and responsive to criticism, applying advances in methodology, and developing systems for quality improvement.
9. Continuity, by ensuring that responsibility for reviews, editorial processes and key functions is maintained and renewed.
10. Enabling wide participation in the work of the Collaboration by reducing barriers to contributing and by encouraging diversity.

Source: Canadian Cochrane Network and Centre

Apart from a precise search process, this part of the content building process is crucial for the quality and reliability – and therewith – the usefulness and success of a website such as EELDA. Critical appraisal is not similar to summarising or abstracting scientific text. Critical appraisal means that scientific studies are assessed on a number of key criteria. These criteria include an assessment of study design, validity of its outcomes, its usefulness for answering the research question and its use for (clinical) practice.

Depending on the experience and role of staff involved in a project such as EELDA, different easy accessible resource publications are available that may prove useful for improving understanding and know-how regarding search methods and critical appraisal methods in evidence-based medicine.

For project staff involved in EELDA type projects, but who are not directly concerned with critical appraisal, Crombie (1996) has written a very accessible 'pocket guide to critical appraisal'. This practical handbook provides a basic introduction to the principles and processes involved in critical appraisal, helping the researcher to make sense of the overwhelming mass of medical literature available. The publication is divided into two parts. The first provides a basic introduction to the principles underlying critical appraisal and details the process of appraisal, identifying the types of questions to be asked of each paper. The second part consists of checklists, each annotated with explanatory text, designed to accompany researchers on library visits and help them make sense of the overwhelming mass of medical literature. Chapters include identifying research methods, interpreting results, appraising surveys, cohort studies, clinical trials, case control studies and review studies.

For scientific authors, a more in-depth publication on how to read scientific (medical) research papers has been written by Greenhalgh (2006). The book provides a basic introduction to evidence based medicine: how to find a medical research paper, assess it for its scientific validity, and where relevant, put the findings into practice. The book is written for those people who wish to understand evidence based medicine.

For more experienced scientific authors and information specialists, Heneghan and Badenoch (2006) have written an 'Evidence-based Medicine Toolkit'. The book offers a guide to the skills of evidence-based medicine. It offers more up-to-date guidance as well as sections on important areas of research. It

includes a box for each major database showing how to search the evidence, new critical appraisal sections on qualitative research and economic evaluation as well as an expanded list of EBM resources on the internet.

In the EELDA content building process, the literature that passed the literature selection was subsequently appraised by the scientific authors. For this purpose, specific critical appraisal protocols had been developed, taking into account the specific characteristics of each key aspect in the website. The critical appraisal tools are used to assess the quality, relevance and conclusiveness of the literature that is retrieved.

Key questions that were raised during the appraisal process included:

- is the study valid (and appropriate for the research question)
- are the results of the study important (are there significant outcomes)
- are the results of the study useful (do they contribute to answering the search question)

Important elements that were part of the critical appraisal process included:

- What study types are included/ excluded (e.g. animal studies)?
- How can the relevance and quality of the study be assessed?
- What to do with 'grey' and unpublished literature?
- Communication with information specialists → refining searches
- Recall and precision
- Averting scientific bias → in/ excluding studies or databases; not following procedures
- Taking notes regarding in- and exclusion of articles

One important issue setting up an appraisal structure for scientific literature has to do with the grading of evidence and with determining when evidence is considered *strong* or *weak* enough. There are no international standards for the grading of evidence, but there are examples of good practice. For example, strong evidence might involve at least one systematic review and at least three RCT's for a specific condition or intervention. It is important to determine in advance which grading system is used and whether this system needs to be aspect specific (e.g. in many harm reduction (public

health) interventions, the number of RCT's is limited, while in medical research or research into the psychological effects might include several high quality RCT's).

The choice of different grading systems for different aspects does not mean that the standards are lowered for one type of area compared to the other. The quality of evidence also has to take into account the context. Nevertheless, once established, the grading system needs to be universally adopted by all authors. For the EELDA project, a grading system was developed for each of the aspects (effects, risks, prevention and treatment).

The management of the critical appraisal process also requires a lot of attention. As many search questions are set out at the same time from different authors and the feedback from librarians might have a different order, sequence and intensity per search request, it is important to implement a tracking system that identifies each specific search question throughout the content building process. In the EELDA project, this could be done eventually through the 'jobs' function of the e-Community, but if such a function is not available, the overview should be created and kept through ID numbers per search and a status overview system through which it is made clear to staff involved who is working on which specific file.

5.6 AUTHORIZING AND SUMMARISING SCIENTIFIC TEXT

After the selection of high quality and relevant studies, the evidence-base can be described and summarised for each of the sub-aspects of the EELDA website. Depending on the number of studies found, each of these has to be completely read and summarised in key-characteristics and conclusions. As each paper is written in a different style, the summary has to be tailored to the needs of the end user of EELDA.

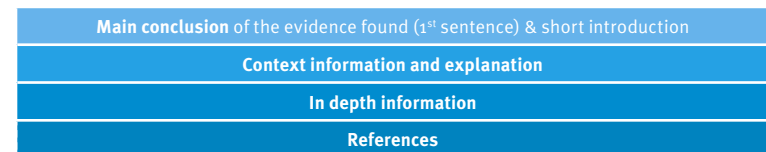
Special attention has to be paid to the text style and language used. The content has to be written for the web, in style and browser added value. This means short sentences, references, Meta tags, hyperlinks. The content and structure of texts must be predictable, the pages of limited length (max 1.5 pages long). As indicated in the previous chapters, the structure and design of the summarised texts changed over time. Nevertheless, the first sentences in a text are of great importance for keeping or losing

readers. Therefore, the most interesting information should be the first thing visitors read.

The title should reflect the content correctly. The style must be objective and clear with high information density. The content must be easy to scan: put one message in one paragraph, clear lay-out with use of bullets. Use pull communication by letting the visitors determine where they want to go and what they read.

The authors are encouraged to use the same format. A web editor checks and improves the style according to the guidelines above. For EELDA, originally the format presented in figure 5.3 was chosen, but the development about the style is part of continued discussions.

Figure 5.3 – original structure of EELDA summaries



5.7 EXPERT REVIEW OF SUMMARISED SCIENTIFIC TEXT

Although scientific authors follow the common protocols and produce summaries based upon the state-of-the-art of scientific research, it may still be possible that (new) evidence is missed or that the conclusions can be interpreted differently. The expert review is intended to reveal possible flaws in the evidence-base screening process.

The role of experts is to validate the website content and to play an important role in encouraging the use of this information within their areas of expertise. As well-known scientists the experts might also help produce a spill-over effect towards other user communities (e.g. help lines, medical professionals, policy makers).

During the expert review, the summarised texts are reviewed by independent experts and examined for relevance and trustworthiness. Their peer review is important for the level of quality and advocacy in the

scientific community for the scientific outcomes.

The experts EELDA aims to involve are independent and well renowned scientists that have expertise in one of the relevant topic areas (substance or related aspect) of the EELDA website. Furthermore, they need to have a substantial publication record in (international) peer reviewed scientific journals in the field of substance use and related areas and/or a substantial record in drug use and addiction practice. Finally, the experts need to have a good overview of existing literature and research in their field of expertise.

In order to safeguard the quality of the reviews at least two experts should examine the summarised texts of one author. When applicable the experts are also asked to provide information on new and unpublished research for future reference. Typical questions experts are asked to address include:

- Do you think the text you are asked to review is coherent and comprehensive?
- Do you think the text is relevant for the (sub-) theme it is linked to?
- Do you think the authors have selected the most relevant literature for drafting a summary on this specific topic?
- Do you know of any relevant, important studies that have not been included in this summary?
- Do you know of any relevant and important yet unpublished studies on this specific research question?
- Do you think the authors came to the right conclusions?
- Do you miss important information in the section?
- What is your overall opinion about the quality of the information provided on the EELDA website?

5.8 POPULARISING AND EDITING SUMMARIES

As indicated in previous chapters, a key difficulty in producing accessible and useful information for professionals and members of the public that are not drug scientists, concerns the presentation, level of abstract and detail that such texts contain. In the EELDA project, the conclusion was drawn at a late stage that many texts were still too inaccessible due to medical and scientific terminology but also because of the level of scientific uncertainty

and nuance reflecting inconclusive evidence. It is important to identify and present the state-of-play also if no clear conclusions can be drawn. But for non-scientists detailed nuances are often lost.

For the EELDA project it was therefore decided that the summarised texts of the scientific authors would remain largely intact, but these would be placed 'behind' a more popularised, shorter and snappier text that would cover the main issues on each subject. This would be done without violating the conclusions and contents. The level of access would thus be brought to that of a quality newspaper.

5.9 USER PANEL REVIEW

As indicated above already, the user panel review is a very important step in the content building process to assess the usability and accessibility of the drug information website. The reviewed texts are scanned for accessibility and user-friendliness before they are officially published on the website. A panel consisting of potential end-users are asked to examine the texts and indicate whether they are answering relevant questions, whether they are comprehensive, and accessible (clear and understandable) for non-scientists. Website logic, navigation and general use are also examined.

User panel reviews can be done through a questionnaire at a distance, but it is better to arrange specific sessions, in which web site builders, but also authors can participate and observe users' actions when browsing the site. By doing so, first-hand experiences can be shared and users can be asked to search for a specific answer to a question on the site and describe their search steps and their experience with search functions, navigation and browsing, but also regarding their interpretation of the possible answer to the question (and thus reveal potential differences in interpretation).

The user panel should not be asked to evaluate the site before it is well developed and functional.

5.10 TRANSLATION AND PUBLICATION ON WEB

After completing the review cycles the texts are published on a website that is open for the public. During revisions of the texts, it might be useful to

block pages, so that visitors understand that new content might be coming soon but also that they do not use possibly outdated information.

As translation costs are high and there might be quite a few changes after some time, it is important that original texts are saved and kept in a well archived record, so that translators can be provided with original texts (as present on the site) and only have to update the last versions of the content. This saves retranslation of existing information.

Furthermore, as the total content of a site such as EELDA might be massive, it is recommendable that only information that is to be presented to the general public (the popularised pages of text) are translated, while more elaborate scientific texts remain accessible in the original (English) language. This might also prevent a major risk when translating EELDA type information. Topics can be quite specific at times and the nuances that are introduced in the scientific texts might not translate into other languages so easily.

It is recommended that translations and updates are done section by section (or aspect by aspect) and that updates are translated in a bulk rather than one by one.

The publication of the website must receive some attention as well. In Chapter 6 reflections on site promotion and maintenance are presented.

5.11 FINALLY

The content building process is an ongoing procedure. Once content has been produced, this content needs to be reviewed and updated if the site is to remain relevant and useful. Therefore, the process can repeat and – hopefully – improve and innovate itself, so that routines become better tuned and outcomes even more relevant for the end user.

Site promotion and maintenance

6



6.1 SITE PROMOTION AND COPYRIGHT

The ambition of the EELDA website is to obtain a leading role within the scientific and professional community in the field of drugs and drug addiction. Some important questions that can be asked when planning the promotion of an EELDA type website include:

- What is unique about this site? What are its unique selling points?
- What is the image the website should convey to its target audience? How should visitors perceive the site after having visited it?
- Who are the main target groups for the website?
- How can these target groups be reached and what tools are required to do so?
- What potential problems may occur when the site is published? Are there any controversial issues?
- Is the technical infrastructure catered to deal with the perceived volume of visitors and are consequences of their visits foreseen (e.g. number of downloads)?

For the EELDA website, some of the *unique selling points* were identified as follows:

- *Reliability*: high quality, evidence-based information on drugs
- *Accessibility*: scientific information presented in a concise and accessible way for an audience other than drug experts.
- *Up-to-date*: information on the site is relatively new, taking into account new studies.
- *Revealing uncertainty*: the site also reveals information on drugs that is still inconclusive and/or for which there is not enough research available.
- *All-in-one*: for each of the covered substances, the most important and complete information is included.
- *Transparency*: this aspect is related to reliability. It must be clear to visitors what the origin of the information provided is, i.e. who the authors are and what research methods they have used.

The unique selling points of the site– in an indirect manner – also reflect the perceived image visitors should have of the website. During the user panel review and visitor surveys it is possible that the perception of the users of the site is ‘tested’ on these criteria.

In Chapter 1, the target group for the EELDA site was identified. It is important – at the end of the initial implementation phase – to double check if the end result is still targeting these previously identified groups. The user panel review will provide information on this issue as well. It is important to know this as it guides the promotional activities.

The methods to reach the target groups can be many. For the EELDA project, conference presentations, business size info cards with the web address and posters were developed for a variety of audiences. The information provided on these communication tools did not reveal much of the contents, but aimed to trigger curiosity with the slogan ‘The most addictive site on drugs’.

Tools to promote the site may further include:

- Presentations at relevant conferences
- Publication of review articles in drug related journals
- Links to and from other websites (although this should be done with care)
- Email news alerts on new content for registered visitors
- EELDA can be promoted as resource database for other information sources and websites. Information can be used (with reference)
- Search engine optimising activities can be undertaken, i.e. by clear meta-tagging and labelling of pages and topics.
- Use can also be made of tools such as RSS. RSS is a format for syndicating news and the content of news-like sites, including major news sites. EELDA could generate RSS feed.

User registration and password protection complicates the accessibility of a site and makes it possibly less attractive. Once the website is published on the internet there is no control on further dissemination of the content of the site. On the EELDA website, visitors will find a copyright statement that stipulates that *“the materials contained in the site may be downloaded or copied provided that all copies retain the copyright and any other proprietary notices contained on the materials.”* It is, however, difficult if not impossible to check how content is being used.

6.2 MAINTENANCE AND DISSEMINATION

Insights in the field of drugs and drug addiction are changing rapidly. It is therefore crucial that the EELDA website is kept up to date. New scientific findings need to be reflected in the content of the website, provided it meets its quality standards.

The content production processes described above ensure high quality data at launch time. It is critical that the proper content maintenance processes are in place as well. In order to prevent that the site is continuously under construction, it is advisable that the team develops a maintenance and update strategy for the website. This strategy may include an update protocol and a planning, which takes into account the intensity of research developments in specific fields and/or any important studies that are underway and expected within a specific time frame. In general, it is advisable to implement updates for each section with regular intervals, i.e. every 6 months.

Follow-up projects will have to allocate time and budget for the review of the current content in terms of accuracy and timeliness of the information. Ideally, keeping the website information up-to-date should be part of daily work tasks of the authors. The project partners should agree on this principle before the end of the project.

In short, a maintenance and dissemination plan may include the following features:

- A time-table: a planning for updating the specific parts of the site
- An update protocol: who does what, when and how?
- A resource planning document: what resources are required in what period and what staff needs to be involved?



In order to keep a website such as EELDA attractive and increase its use by potential target audiences, it is also important that the site is revised and improved on a continuous basis. This may include:

- A strategy to inform visitors about updates: making changes visible
- The expansion of the content of the site, e.g. with:
 - New substances and/ or aspects
 - Background information on risk assessment models
 - Background information on study types and how to interpret them
 - Possible guidelines for the assessment of prevention and treatment programmes
 - Links to articles and publications
 - Editorial reviews of new reports and studies
- Providing relevant 'news' updates and background information on current substance specific discussions and debate in society.



6.3 DISCLAIMER AND LEGISLATION

One of the important issues to be addressed when building a website such as the Evidence-based Electronic Library for Drugs and Drug Addiction (EELDA), concerns the issue of liability. The website needs to include a disclaimer, protecting its owner from any liability. For the EELDA site, the following disclaimer was developed.

Disclaimer

This website was developed with financial support from the Commission of the European Communities. The contents of this website are the responsibility of and reflect the views of the Trimbos Institute, IDT and DrugScope. The European Commission is not liable for any use that may be made of the information contained in this website.

Links

All links from this web site have been selected using a standard links protocol. Links are provided for information and convenience only. We cannot accept responsibility for the sites linked to, or the

information found there. A link does not imply an endorsement of a site; likewise, not linking to a particular site does not imply lack of endorsement.

Accuracy

While we have taken every care to compile accurate information and to keep it up-to-date, we cannot guarantee its correctness and completeness. The information provided on this site does not constitute business, medical or other professional advice, and is subject to change. We do not accept responsibility for any loss, damage or expense resulting from the use of this information.

Availability

We cannot guarantee uninterrupted access to this website, or the sites to which it links. We accept no responsibility for any damages arising from the loss or use of this information.

6.4 FINAL REMARKS

As indicated in the beginning of this publication, the guidelines and information provided in the previous chapters is not exhaustive. During the implementation of the EELDA project, many unforeseen problems occurred that required a solution.

EELDA was a new type of project for all involved project partners. In the beginning it was not clear to all partners involved how the final product would look like. In such situations, when the outcome of an innovative project has not yet been completely worked out, it is important to pay attention to potential risks and assumptions that may influence the outcome. By doing so, possible responses to reduce potential risks might be thought of in advance.

And even with all the best care and efforts that are put into a project like EELDA, there is in the end only one group of people that decide whether it was a success: the end-users of the information that is provided.



RECOMMENDED LITERATURE

Crombie, I. [1996]. *Pocket Guide to Critical Appraisal*. BMJ Books, United Kingdom.

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Sackett, D.L. et. al. [2000]. “*Evidence-based Medicine: How to Practice and Teach EBM*”. 2nd Edition, Churchill Livingstone, Edinburgh, ISBN: 0-443-06240-4.

Ter Meulen, R. & Biller-Andorno, N. & Lenk, C. [2005]. *Evidence-Based Practice in Medicine and Health Care: A Discussion of the Ethical Issues*. Springer Verlag Inc., Germany.

LIST OF ABBREVIATIONS

ATS	Amphetamine Type Stimulants
CMS	Content Management System
DG SANCO	Directorate General Consumer Protection and Health (EC)
DSM	Diagnostic and Statistical Manual of Mental Disorders
EDDRA	Exchange on Drug Demand Reduction Action (EMCDDA)
EELDA	Evidence-based Electronic Library for Drugs and Addiction
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
HEN	Health Evidence Network (WHO)
NIDA	National Institute on Drug Abuse
NREPP	National Registry of Evidence-based Programmes and Practices
RCT	Randomized Controlled Trial
WHO	World Health Organisation

GLOSSARY

Case-control study: people with the outcome of interest (cases) are matched with a similar group without it (controls) to see if there are any differences in their exposure to a causative factor. These studies are often retrospective.

Clinical trial

A clinical trial is a study that is used to test whether one health care intervention is superior to another. Clinical trials are often described in terms of testing drugs, but they can be used to investigate many different types of health care intervention, including vaccination and health education. Clinical trials are always concerned with effectiveness. A characteristic of well-conducted clinical trials is that they identify a set of patients with a diagnosed disease, and then randomly allocate them to new or current best treatment. The focus of the study is on the outcome of the treatments, seeking the one which is superior. Clinical trials are also concerned with the side effect of treatments.

Cochrane collaboration

The Cochrane Collaboration is an international non-profit and independent organisation, dedicated to making up-to-date, accurate information about the effects of healthcare readily available worldwide. It produces and disseminates systematic reviews of healthcare interventions and promotes the search for evidence in the form of clinical trials and other studies of interventions. The Cochrane Collaboration was founded in 1993 and named for the British epidemiologist, Archie Cochrane. The major product of the Collaboration is the **Cochrane Database of Systematic Reviews** which is published quarterly as part of The Cochrane Library. [<http://www.cochrane.org/reviews/clibintro.htm>].

Cohort study: people who have been exposed to the intervention or causative factor are matched with a similar group who have not been exposed to it and followed forwards to see if they develop the outcome.

Cross-sectional survey: a defined group of people are assessed at a given point in time to see if they have the condition of interest.

Database of Systematic Reviews which is published quarterly as part of The Cochrane Library. [<http://www.cochrane.org/reviews/clibintro.htm>].



DSM-IV

Diagnostic and Statistical Manual of Mental Disorders, IV edition. This manual includes a diagnostic terminology of psychiatric and psychoactive substance use disorders classified by the American Psychiatric Association (APA).

Evidence-based medicine

Evidence-based medicine consists of carefully, explicitly and judiciously using recent scientific evidence for medical decision making for individual patients. The practice of evidence-based medicine implies an integration of individual clinical expertise with best evidence available in systematic studies. Preferences and expectations of individual patients play a major role in decision making.

Meta-analysis

Meta-analysis is the statistical component of a systematic review (see systematic review) in which the outcomes of similar studies are statistically drawn together to a mean outcomes for all or for subsets of studies. In the international literature, the terms systematic review and meta-analysis often are used interchangeably.

Prevalence

Prevalence is a statistic of primary interest in public health because it identifies the level of burden of disease or health-related events on the population and health care system. Prevalence represents new and pre-existing cases alive on a certain date, in contrast to incidence which reflects new cases of a condition diagnosed during a given period of time. Prevalence is a function of both the incidence of the disease and survival.

Randomised controlled trial: people with the condition of interest are randomly assigned to receive either the intervention of interest or a control regimen and are then followed forwards to see if they develop the outcome of interest. Randomisation is meant to minimise systematic bias in outcomes. Outcomes are assessed and explained by rigorous comparison of groups on rates of disease, death or recovery. RCT's are the most powerful method of eliminating (known and unknown) confounding variables and permit the most powerful statistical analysis (including subsequent meta-analysis).

Systematic review

An article in which the authors have systematically searched for, appraised, and summarised all of the (medical) literature for a specific topic.





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