



**EUBIROD**  
EUropean Best Information  
through Regional Outcomes in Diabetes



## **WP4 TRAINING**

**DELIVERABLE D4.1**

**Report on Training**

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## **1. Introduction**

EUBIROD aims to implement a sustainable European Diabetes Register through the coordination of existing national/regional frameworks and the systematic use of the BIRO technology. The system will fulfill the Conclusions of the EU Council for the systematic data collection and monitoring of diabetes complications and health outcomes across Europe.

EUBIROD targets the sustainability of complex systems of health indicators requiring continuous update and regular maintenance. The project proposes an action to implement, extend, and customise the application of the BIRO technology in at least 20 States, including EU Member States, Acceding/Candidate Countries, and EFTA Countries.

Participants will be connected through a system that will safely collect aggregated data and produce systematic EU reports of diabetes indicators, which will be used to develop recommendations for policy makers.

The EUBIROD Consortium includes all BIRO Partners and N=12 new Partners coming from all over the Europe and two collaborating institutions.

The extension of the BIRO system to the whole EUBIROD Consortium required, as preliminary step, to disseminate the BIRO approach, to effectively train new Partners on the BIRO solutions and to prepare them for the uptaking of the technology.

This report aims at summarizing the activities done and the achieved results. After the first year of the EUBIROD Project we evaluate the progress status e we define new action lines for the prosecution of the project.

## 2. Objectives

The aim of the EUBIROD work package 4 "Training" is to introduce the BIRO approach to N=12 new Partners and N=2 Collaborating Institutions that have not been previously involved in the BIRO Consortium.

The specific objectives of this work package are the following:

- o to provide new Partners with a summary of activities and achievements of the BIRO Project
- o to provide new Partners with all pointers to BIRO materials, in particular an in depth reading of all BIRO deliverables/reports available
- o to distribute the most updated version of the BIRO system to all partners
- o to organize a test run of the BIRO system to concretely show the capacity of the software using test/real datasets to deliver the local and global BIRO reports

The effective accomplishment of the training objectives represents the first important milestone of the EUBIROD Project.

The main intention of the training session was to provide an opportunity to test the quality of the BIRO system in terms of effectiveness, simplicity and usability for third parties. Direct impressions of participants was required to help improving the process and developing proper tools to facilitate usage of the software.

### **3. Materials and methods**

The following actions were planned to fulfill the specific objectives of training:

- organization of the First BIRO Academy Residential Course
- design and implementation of the Training section of the BIRO Academy website
- distribution of the BIRO Monograph

### **3.1 First BIRO Academy Residential Course**

The first BIRO Academy Residential course was held at the Dasman Center for Research and Treatment of Diabetes in Kuwait City on 2<sup>nd</sup>-4<sup>th</sup> May 2009. The event was dedicated to the dissemination and training in EUBIROD.

The course was split in a lecture session and a practical session. Introductory materials were provided at the start of the session.

#### *Introductory materials*

The following documents were circulated among partners before attending the meeting:

- Technical requirements for datasets to be provided as input to the BIRO Software (see Appendix A). The document describes data elements needed for the routine use of the BIRO software (merge table, activity table, population table, diabetic population table). An extract of the BIRO Common Dataset has been also include to provide details on BIRO fields and their format.
- Questionnaire on data availability at each partner site (see Appendix B). The questionnaire aimed at collecting information on any dataset available for the practical session that would be directly used by each partner for own training. Further information on notebooks (hardware/software) that would be eventually brought to the session by participants was also requested to organize the venue at best convenience. Partners were kindly asked to provide feedback two weeks before the meeting.

#### *Lecture session*

The main aim of the lecture session of the Course was to induct partners of the EUBIROD Consortium to the approach developed in the project "Best Information through Regional Outcomes" (BIRO). Lectures directly from WP leaders allow to disseminate the scope, the materials and the results delivered by the Consortium to a wider international audience.

Complete multimedia coverage of the session was ensured by the Dasman Center and has been translated into flash format to be conveniently made available online.

Lectures were provided by a selected international panel of thirteen experts, the "BIRO Faculty", involved in the development of the BIRO system and using diabetes information for policy making on a routine basis.

Lectures were organized around four themes: the first three of technical nature (Background, Objectives and Data; The BIRO System; Implementation and Usage), the fourth focused on policy (Regional Diabetes Registries for policy and practice). Themes include a final discussion allowing the audience to interact with the Faculty and stimulate provocative comments, as witnessed by the abstracts and video

coverage.

The content of lectures is explored in great detail in the EUBIROD Deliverable D2.1 "BIRO Academy Residential Course Year 1".

### *Training Session*

Aims of the training session at the First Residential Meeting in Kuwait were:

- to induce EUBIROD partners not experienced in the BIRO system to the approach and its practical application, using software on test datasets either extracted from local registers, or directly supplied by the EUBIROD Coordinating Centre as a software bundle
- to introduce all EUBIROD partners to the use of the BIRO Box, an interactive Graphic User Interface (GUI) that integrates all BIRO functions into a comprehensive tool.

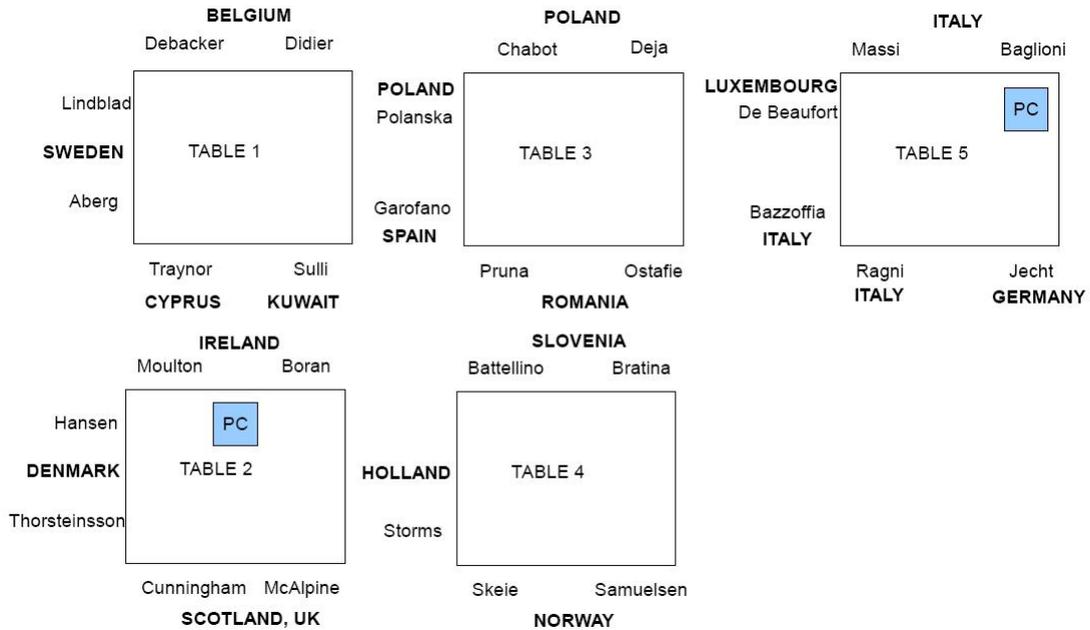
Participants to the training session are listed in Table 1.

Table 1. List of Participants to the training session

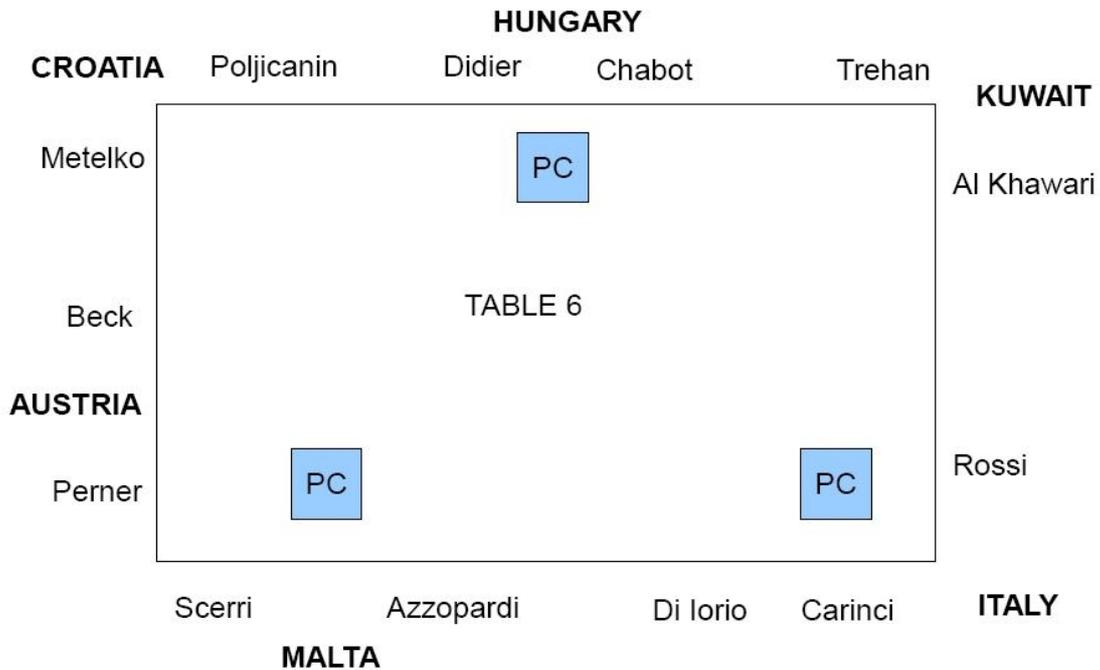
<p>                 Åberg Lars Mikael, NEPI Foundation, Malmö, Sweden                  Adány Róza, School of Public Health, University of Debrecen, Debrecen, Hungary                  Al Huwail Dari, Ministry of Health, Kuwait                  Al Khawari Mona, Amiri Hospital, Kuwait City, Kuwait                  Awaraji Christian, Dasman Center for Research and Treatment of Diabetes, Kuwait City                  Azzopardi Joseph, University of Malta, Malta                  Baglioni Valentina, University of Perugia, Perugia, Italy                  Battelino Tadej, University Children's Hospital, Ljubljana, Slovenia                  Bazzoffia Marco, University of Perugia, Perugia, Italy                  Beck Peter, Joanneum Research, Graz, Austria                  Boran Gerard, The Adelaide and Meath Hospital Dublin, Ireland                  Bratina Nataša Uršič, University Children's Hospital, Ljubljana, Slovenia                  Carinci Fabrizio, Sereatrix, Pescara, Italy                  Cunningham Scott, University of Dundee, Dundee, Scotland                  de Beaufort Carine, Centre Hospitalier de Luxembourg, Luxemburg                  Debacker Noemi, Inst. Scient. Santé Pub. WIV, Brussels, Belgium                  Deja Grażyna Elzbieta, Medical University of Silesia, Katowice, Poland                  Di Iorio Concetta Tania, Sereatrix, Pescara, Italy                  Didier Edwin, Inst. Scient. Santé Pub. WIV, Brussels, Belgium                  Garófano Daniel, IMABIS Foundation, Malaga, Spain                  Hansen Charlotte Irene, Hillerød University Hospital, Hillerød, Denmark                  Jarosz-Chobot Przemyslaw Krystyna, Medical University of Silesia, Katowice, Poland                  Jecht Michael, Havelhöhe, Berlin                  Lindblad Ulf, NEPI Foundation, Malmö, Sweden                  McAlpine Ritchie, University of Dundee, Dundee, Scotland                  Metelko Želiko, Vuk Vrhovac University Clinic for Diabetes, Zagreb, Croatia                  Moulton Anthony, The Adelaide and Meath Hospital Dublin, Ireland                  Nagy Attila, School of Public Health, University of Debrecen, Debrecen, Hungary                  Ostafie Cristina, Institute "N. Paulesco", Bucharest, Romania                  Perner Philipp, Joanneum Research, Graz, Austria                  Polanska Joanna, Medical University of Silesia, Katowice, Poland                  Poljičanin Tamara, Vuk Vrhovac University Clinic for Diabetes, Zagreb, Croatia                  Pruna Simion, Institute Paulescu, Bucharest, Romania                  Rossi Luca, University of Perugia, Perugia, Italy                  Samuelsen Kristian, NOKLUS, Bergen, Norway                  Scerri Simon, University of Malta, Malta                  Skeie Svein, NOKLUS, Bergen, Norway                  Storms Fred, CBO Dutch Institute for Healthcare Improvement, Utrecht, Netherlands                  Thorsteinsson Birger, Hillerød University Hospital, Hillerød, Denmark                  Traynor Vivie, Ministry of Health, Cyprus                  Trehan Sachin, Dasman Center for Research and Treatment of Diabetes, Kuwait City             </p>
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*Organization of the training venue*

Trainees were allocated to different tables in two separate rooms (see Figure 1 and Figure 2). Participants were mostly equipped with own notebook, except for five partners who did not bring their laptops, then provided by the Dasman Centre with desktop PCs, fully loaded with the required software installed by the Coordinating Centre on both Windows and Linux platforms.



**Figure 1 – Training venue room 1**



**Figure 2 – Training venue room 2**

### *Supporting team*

A supporting team was nominated to solve all technical problems, including Dr.Baglioni, Dr.Carinci and L.Rossi from the Perugia Coordinating Centre, and Dr.Awaraji, Dr.Trehan from the Dasman Centre.

The training session was split over the three days of the meeting according the following schedule:

- the first afternoon, to introduce technicalities and to prepare all computers for the application of the BIRO system through the installation of software components distributed by third parties (e.g. Java, R, Latex, etc). Here the plan was also to export test/local data to the XML BIRO format.
- the second afternoon, dedicated to introduce a case study on the standardization of Kuwait data for the statistical analysis and direct usage of BIRO, followed by the continuation of the previous session to carry out basic statistical analysis and further processing of aggregate data
- the third morning, to produce the BIRO reports

The session was initiated by an introductory talk by Dr.Carinci, Technical Coordinator of the EUBIROD project, and a presentation by Dr.Baglioni, EUBIROD project manager, software engineer and major developer of the BIRO Box, on the various IT components.

As a first step, Dr.Baglioni introduced the technical aspects of the Box by reminding the major features of the system also presented at the BIRO Academy.

The training session was designed around four phases:

- setup of all software components
- database load operations
- local statistical analysis
- global statistical analysis

Finally, the training activity was enriched by the speech of Mona Al Khawari, Head of the Diabetes Pediatric Division, Al-Amiri Hospital, Kuwait, who presented the contents of the database maintained at the Division, explaining how it was possible to process and analyze the data in preparation of the BIRO training session.

### *First training phase: setup*

In the initial setup phase, Dr.Baglioni introduced a list of mandatory prerequisites that needed to be satisfied in order to install the BIRO system (see Appendix C). These steps mainly consisted in downloading and installing software packages by third parties, as well as setting environmental variables for the operating system.

This step proved to be the most difficult aspect of the whole session, as reflected by responses to an evaluation questionnaires that the Coordinating Centre has submitted to all participants afterwards.

### *Second training phase: database load operations*

The phase of database load operations was split in two different rounds:

- exporting data to the BIRO XML format
- loading data on the Postgres database

The aim of this round was to export any data table from a diabetes register in a format that could be read by the BIRO system and be loaded into a BIRO-standardized Postgres database.

Both steps can be bypassed by a centre having the capacity to directly translate local datasets (i.e. all tables required by BIRO) into the BIRO Postgres database. This is normally the case of large centres with a substantial expertise in IT and data management. On the other hand, for those relying entirely on the BIRO system, both steps are required.

The objective of the first step was to produce a zip file - whose dimension depends from the size of the origin dataset - including all XML files for patients in the register according to a consistent BIRO format. The latter may be only a subset of larger databases maintained by the contributing unit.

Such an option is important to grant flexibility to the system: if a small centre does not have the capacity to run a Postgres database (which in many instances may be very likely), then the operator has the opportunity to produce the export using the stand-alone BIRO Box, referring to another centre (e.g. a "Regional", or "National BIRO coordinator") to upload BIRO exports and manage the Postgres database. The coordinating centre will then be able load all exports into own database. Noticeably, such a case falls outside the scope of the BIRO system (will require separate agreements), as the coordinating entity will exchange and manage individual data from associated centres rather than aggregated data.

Diabetes registers are usually based on heterogeneous data entry systems with own coding. The choice made by the BIRO project is to leave this situation unaltered and to deal with complexity, to avoid any additional burden for contributing units.

To export local data into the BIRO format, it is then required to "map" from local coding to the BIRO coding. Although this could be done autonomously by each unit by referring to the specifications provided by the Common Dataset and Data Dictionary, the BIRO development team designed a custom application to perform this operation, that has been fully integrated in the BIRO Box and was applied at the training session.

### *Third training phase: local statistical analysis*

The phase of local statistical analysis consisted in running the local statistical engine to produce the BIRO reports. In BIRO, the statistical engine connects directly to the Postgres database, then it loads target fields and produces the report of diabetes indicators.

*Fourth training phase: global statistical analysis*

The program for this phase included sending the statistical objects to the central engine (BIRO server software) and producing the overall BIRO report.

Since the operations for the use of the local statistical engine required a much longer time than initially expected (see "results"), this phase was later replaced by a "wrap up" session that partners agreed to be more useful at this stage.

### 3.2 BIRO Academy web site

A new web site has been designed to present the activities and materials related to the BIRO Academy. At the moment the BIRO Academy web site is a sub section of the EUBIROD web site and it can be reached at the following address: [www.eubirod.eu/academy/index.html](http://www.eubirod.eu/academy/index.html)

The web site contains a short introduction about the aims and strategies of the Academy. In the section dedicated to the first Residential Course, the users may browse the lectures, the training material and the photo gallery of the meeting. Each lecture is accompanied by a summary description of the content, a flash movie, and a link to the slides. The training section contains an extended technical description of the activities and the related achievements. Links are provided to the statistical reports obtained as a result of the training. The photo gallery contains pictures of the Dasman Center and pictures showing the main phases of the meeting. The home page of the web site is represented in Figure 3.

BIRO software, including the version provided during the first training session, can be found under the "BIROBox" section.

Currently the access to BIRO Academy web site is restricted to EUBIROD partners and representatives of supporting institutions. In the second year of activity, we anticipate the preparation of a subscription form, through which interested users ("BIRO Alumni") will be granted access with login from the Academy homepage, directly accessible from the unrestricted area of the EUBIROD website.



Figure 3- BIRO Academy web site

### **3.3 BIRO Monograph**

The electronic version of the monograph has been made available to the whole Consortium for the Training Session held in Kuwait.

A hardcopy will be distributed to all Partners during the First EUBIROD Technical Meeting to be held in Rome on 19<sup>th</sup>-20<sup>th</sup> November 2009.

The BIRO Monograph is a fundamental volume for the dissemination of the BIRO approach and training activities as it summarizes results obtained from more than 30 deliverables into a comprehensive publication of about 200 pages. The book includes an appendix with short guide to the BIRO software.

The monograph consists of four major sections.

The first section presents the background of the project, its mission and an overview of the activities performed.

The introductory section is followed by a chapter dedicated to the expected outputs, i.e. the set of process and outcomes indicators tracked by the BIRO system, plus the specific format adopted to present them to each user category.

The third section explains the BIRO System architecture in detail. All architectural components and how they integrate into a comprehensive system, going through the methodology of privacy impact assessment to the selected design of the BIRO architecture, and how it has been implemented.

The monograph is ended by a chapter about the perspectives of BIRO system in terms of its extendibility, scalability, and possibility to enter routine use within the framework of the European Health Information System.

## **4. Results**

Results of the training session held at the First BIRO Academy Residential Course can be presented through achievements of each of the four phases carried out at the meeting.

## 4.1. Achievements

### *First training phase: setup*

This step proved to be the most difficult aspect of the whole session, as reflected by responses to an evaluation questionnaires that the Coordinating Centre has submitted to all participants afterwards.

Countless problems were encountered while carrying out setup operations. The variability of problems was very high, and challenging: many problems occurred only on some specific PCs. That was most likely due to heterogeneous operating systems and the different hardware available.

User permissions gave also substantial problems: some notebooks were property of the partner organization whose policy did not provide administrative privileges to end users. Although the Coordinating Centre explicitly requested for privileged to be granted in advance, users came unprepared to the meeting.

Even when administrative privileges were granted, computers powered by Vista behaved in strange ways, making the entire process difficult, particularly when setting environment variables.

Some packages available online from third parties (in particular, Mixtex and Postgres) did not install properly on specific machines, apparently for no reason.

As a result, the supporting team was not always able to find quick solutions to basic installation problems and this created a state of uncertainty among participants about the possible achievements.

Indeed, these difficulties show the following:

- it is not possible to foresee all problems without a direct application of the software in real life conditions. A shared information systems e.g. BIRO requires to be compliant with many different environments. Although frustrating for partners, the experiment must be regarded as very useful for software developers, as it may trigger new solutions to overcome complex operations and reduce installation bugs

- open source software can be very convenient, but it requires downloading and installing tons of different packages/libraries from third parties. These solutions must be tested on different systems before being adopted. A trade-off must be identified to match the user needs (all operating systems, old and new machines, etc) with the developer needs (upgrading software). As a result, it might be necessary to fix stringent minimum requirements for machines running BIRO.

- Internet connection may slow down considerably when many users download huge files from same repositories. Cable connection should be preferred over wireless.

PCs powered by MS Windows may be easier to use, but as more flexibility is demanded, they can show unexpected problems, that are difficult to overcome even by expert users. On this ground, Vista is perhaps the worse case to handle. On the other hand, Linux machines may be less used, but they are much easier to operate, and open source software is native to them. This means that as problems occur, their

resolution by a team of experts e.g. the supporting team may be almost immediate.

To make more efficient usage of time, it will be advisable to carry out a remote setup and assist users with a hotline well in advance of the meeting.

The supporting team should be more evenly balanced across users to intervene faster as problems occur. They must be also more coordinated in preparation of the session by sharing the definition of the materials.

The last step required, i.e. installing the BIRO Box, did not create any problem once all requisites for setup have been satisfied. For partners who were unable to finalize the first part, the Coordinating Centre provided a desktop computer fully functional with regards to using the BIRO system.

### *Second training phase: database load operations*

The aim of this round was to export any data table from a diabetes register in a format that could be read by the BIRO system and be loaded into a BIRO-standardized Postgres database.

To export local data into the BIRO format, it is required to "map" from local coding to the BIRO coding. Although this could be done autonomously by each unit by referring to the specifications provided by the Common Dataset and Data Dictionary, the BIRO development team designed a custom application to perform this operation, that has been fully integrated in the BIRO Box and was applied at the training session.

In most cases, the tool worked fine. However, we found that so many conditions are present in original databases, that it is practically impossible to cover all possible mappings. Therefore, some minimal requirements must be met to optimise the process.

Despite of the very few mandatory items required in a BIRO database, some of them were not met by the local registers. Some items apparently straightforward (e.g. type of diabetes, date of diagnosis, etc) were not so obvious in a practical situation. To solve this problem and advance the analysis, in some cases it was necessary to change the original data, either by adding a dummy field and populating the database, or eliminating errors in dates, etc.

Our experience shows that it is necessary to improve the original databases. There is a need for more training at the local centre, and upgrading local database software, including quality checks that are evidently not present. For instance, Excel spreadsheets frequently hide improper format, which once exported cause consistency errors.

By the way, the most convenient situation is the one in which registers are started using the BIRO format, as in the case of Cyprus, or revised to comply with it.

By all means, the BIRO mapping tool, connected to the Java-based "Adaptor" to export data, proved to be quite a robust application, as it avoided for the majority of inconsistent fields to be translated into the standardized BIRO export.

Nevertheless, it still needs to be improved by adding detailed log messages in the application, indicating the exact position of inconsistent data. Experience shows that when errors are found either the process suddenly breaks (meaning that no export is

produced), or result in XML files with missing data/fields.

Some of these inconsistencies were then reflected in the second step, i.e. loading data into the Postgres database. When important data/columns were missing, the relevant tables were not created in the database, causing problems to the statistical engine.

At the end of this round, with substantial help and data tweaking from the supporting team, almost all partners succeeded in loading the database, either by using own data, or reverting to use the test data provided by the Coordinating Centre to complete the training session.

### *Third training phase: local statistical analysis*

The phase of local statistical analysis consisted in running the local statistical engine to produce the BIRO reports.

At this stage, errors that were not discovered in the previous round became evident, since the engine would naturally stop when data, particularly mandatory fields, were not properly translated into the Postgres database. That occurrence triggered a trial-and-error phase in which the supporting team had to check all fields carefully and eventually correct original data to repeat steps previously performed without success.

The source code of the statistical engine was also improved to take into account unexpected situations and several bugs were corrected.

### *Fourth training phase: global statistical analysis*

The above steps needed to be repeated while partners were progressively able to deliver own reports. At the end, many partners succeeded in delivering correct reports, first of all Germany, Austria, Malta, Poland, Croatia, Kuwait. However, operations for the use of the local statistical engine required a much longer time than initially expected.

For this reason, the phase of global statistical analysis was finally cancelled and moved to next technical meeting.

The program for this phase included sending the statistical objects to the central engine (BIRO server software) and producing the overall BIRO report. Although possible, partners agreed that a "wrap up" session was more useful to understand the contents of reports and plan improvements. Participants agreed to take the case of Germany as a basis for discussion and examined all outputs in detail, making comments on all indicators.

In conclusion, trainees were very satisfied and enthusiast of the production of the BIRO system. Partners agreed that the system had vastly improved since its first release. The practical outcome is visible, and it can be reproduced in very different conditions.

Partners also examined other reports. In particular, the case of Kuwait was found very interesting, mainly for two different reasons.

Firstly, it shows that a database from a non European country, inexperienced in the approach, can successfully contribute to EUBIROD, producing a data export and a

standard BIRO report.

Secondly, it provides an important message from a clinical perspective, being the only case of a paediatric database in the training session. The case shows that a profound revision is required to apply BIRO to the paediatric population. Indeed, the current report seems inadequate, including many tables with sparse cells, stratified by age groups that are not relevant. Furthermore, many indicators on diabetes complications are meaningless in this context. Partners agreed that a connection with other EU projects dedicated to paediatric diabetes is required.

The training session provided positive results for participants and important indications for further improvement. Partners left agreeing that more materials should be produced to ensure online, everyday use of the software.

## 4.2 Training Questionnaire

In order to collect the Consortium's feedback about the results of the training activity held at the First BIRO Academy Residential Course, the EUBIROD Coordination Centre circulated a questionnaire specifically designed for the scope to all participants (see Appendix D).

Responses received may be browsed in detail in Appendix E. Here follows a brief summary of responses received for each question posed to the attendants.

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?*

Most of respondents found lectures clear, interesting and useful to understand the BIRO approach. Most topics addressed were already familiar to BIRO Partners, who principally acted as BIRO "faculty". The discussions following each lecture theme were considered highly informative, and useful to trigger improvement of applications. In the first course, the lectures had to address a widespread variety of topics in order to create a substantial background on BIRO themes. Some respondents suggested that in the next BIRO Academy course, lectures could be reduced and focused on technical topics so that BIRO Academy might become a tool for technology-transfer between participating partners.

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?*

Respondents asked to explore the following topics in more details at next meetings:

- links among elements of technology
- the prerequisite software needed for BIRO application to work properly, as well as BIRO software setup procedure and options.
- running BIRO software on databases different from PostgreSQL, e.g. MS SQL/mysql
- use of the data beyond production of standard reports
- indicator reproducibility and comparability, as well as the denominator characteristics
- proposed presentation of statistical results in a working prototype of the Web Portal
- further improvements to the Web Portal through the use of fresh information visualization tools
- Case studies of diabetes registers in Europe where the BIRO system is fully applied

**Q1.3:** *Can you suggest any topic that was not covered?*

Although necessary topics were almost completely covered, respondents pointed out that some technical aspects, mainly referred to the concept of information visualization and interaction with the user, should be discussed in more detail. This would allow the BIRO product to be always up to date with respect to the most recent technologies. Many respondents also observed that it would have been appropriate to

circulate more technical details on the BIRO software well in advance of the meeting so that the participant could arrive better prepared at the training session.

Finally, among the missed topics some respondent highlighted a plan for publication of BIRO results and an overview of possible use of BIRO for research purposes.

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?*

Participants appreciated the opportunity to work hands-on with the BIRO system, performing practical exercises on own datasets. This format should be even improved, by increasing the number of exercises and including demo of successful experiences in compiling data. Especially for beginners, it would be beneficial to practice interactively with the BIRO System by testing it on own computer while following the instructions and seeing them presented at the same time.

Participants might be split in small groups, each followed by an expert experienced in the use of the BIRO software, who can timely answer trainees' questions and solve technical problems. In a wrap up session, each working group should report on specific issues arisen. Someone also suggested to differentiate the training activities for technical and clinical participants.

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?*

Participants found venues appropriate, well organized and of high standard. Computers provided by the meeting organizers were already equipped with all the software needed. Unfortunately, too much time was spent for the setup of the BIRO Software and prerequisite software on trainees' notebooks. Again this could be avoided by circulating the setup guide before the meeting or by distributing CDs/USB keys equipped with all the necessary software among participants instead of downloading it from the web. Someone objected split training in two different rooms.

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

Setting up and getting the software running for every one took so long. Even if staff were available to help out the trainees, it was not sufficient to answer all questions and problems of about 50 people. Those waiting too much lost enthusiasm in the training session. For non-informatics was even more difficult to get the system running. Partners felt disoriented because they did not know what to do in specific situations.

The Coordination should have better explained the plan and organized the supporting team at the beginning of the session. It would have been preferable to lead all the partners at the same level of training and continue from there next time instead of having few successful groups. The whole session should have been controlled and planned in advance as in a theatrical representation. In preparation for the next meeting, bugs must be avoided through an extended test session and a contingency plan must be prepared.

**Q2.3:** *Was the introductory description of the usage of the software appropriate?*

The introductory description of the usage turned out to be appropriate for IT people while it was not sufficient people with no IT expertise.

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?*

Out of 16 respondents, 11 worked on their own notebook, 4 worked on a computer provided by the organization and one was part of the supporting team.

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?*

Participants who worked on notebooks with Windows Vista installed, had some problems with the setup and running of BIRO software and prerequisites applications mostly due to the need of administrative privileges. On those notebooks equipped with a different OS, the basic software installations were straightforward. Anyway, since there are many requirements to be met, all the required utilities need to be bundled into one installation routine.

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?*

Most participants provided test datasets extracted from their institutions' databases. This was very interesting for the training activities even if it caused a work overload to the supporting team who had to explore many different datasets in case of anomalous behaviour of the BIRO System. Developers had the possibility to benchmark the system against multiple real situations, which could not be explored otherwise.

**Q2.7:** *Were there any particular problems using the database that you can report?*

With the exception of few trainees who didn't manage to setup the DBMS PostgreSQL properly, in most cases the connection between the BIROBox and the DBMS was successful and didn't cause any problem. As it was expected, the major difficulties arose during the mapping between the local database format and the BIRO format. This requires to be better explained to the users by developing an on-line help and possibly it would need to be improved by adding more encoding criteria.

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.*

Here follows the answers provided, as they were collected by respondents.

"I tried to get the data of the my database into the system installed from BIROBox. After two half days of trying we almost succeeded in exporting the data. The whole group worked together in a proper way and the support from the ICT people of EUBIROD was perfect, but the system was just not sufficiently stable"

"The BIRO System seems not yet ready to be applied in all programs, nor data sets. But some did manage. This indicates that the problems can be addressed and resolved. In a second phase of course the technical problems should be solved. Then the very precise definition of core indicators and their definitions as well as the definitions of the data sources should be prepared, to allow reliable comparison."

"Installing and setting up took some time because of all the different packages and programs involved. I eventually got it working but had to put some of the commands through manually. There were far too many glitches and problems when running the software. It did not work seamlessly, often failing between processes, meaning the administrators had to intervene to allow any jobs running to finish. I managed to generate the report in the end, it was not a straightforward process though. At the same time, I expect a lot of useful lessons were learned by the developers"

"Personally, I found the work very hard because I am a DSN and our IT person was not able to come at the last minute because of a technicality ref. her visa. Nevertheless, all the IT people were helping me out at every step of the way. I know if our IT person was there, we would have been able to do much better"

"Since the software required additional improvements, the process could not be carried out by participants themselves, and required engagement of IT and statistical experts. This interfered with the educational process of the workshop."

"Due to the fact that the system worked out rather fast on my notebook, I went around and helped people to get the software installed and to get the system running on their datasets. Unfortunately I had to fix the same bugs on every partner's installation, so it was really time-consuming. My experience was that the software has not been tested before. It's absolutely necessary to use resources (personnel/money) to test and improve the software before it gets installed by the project members. We have to regard the project-members, which were not part of BIRO, as our first clients, and not as our software-testers. Otherwise people will lose their interest because we are not proceeding in our tasks for the project."

**Q2.9:** *At the end of the session, did you succeed in:*

- a)running the BIRO software (using the BIROBox)*
- b)mapping data from your test dataset to the BIRO definitions*
- c)exporting data in BIRO XML format*
- d)loading data on the BIRO Postgres database*
- e)running the statistical engine*
- f)producing the final BIRO report*

Based on the answers received from each respondent (summarized in table 2), a total of N=9 trainees out of N=16 managed to complete the whole BIRO process and to obtain the full BIRO report.

**Table 2. Responses to Q2.9 of the training questionnaire**

	<b>step a</b>	<b>step b</b>	<b>step c</b>	<b>step d</b>	<b>step e</b>	<b>step f</b>
<b>resp. 1</b>						
<b>resp.2</b>	y	y	y	y	y	y
<b>resp. 3</b>	y	y	n	n	n	n
<b>resp. 4</b>	y	y	y	y	y	y
<b>resp. 5</b>	n	n	n	n	n	n
<b>resp. 6</b>	y	y	y	y	n	n
<b>resp. 7</b>	n		y	y	y	
<b>resp. 8</b>	y	y	y	y	y	y
<b>resp. 9</b>	y	y	y	y	y	y
<b>resp. 10</b>	y	y	y	y	y	y
<b>resp. 11</b>	y	y	n	n	n	n
<b>resp. 12</b>	n	n	y	n	n	n
<b>resp. 13</b>	y	y	y	y	y	y
<b>resp. 14</b>	y	y	y	y	y	y
<b>resp. 15</b>	y	y	y	y	y	y
<b>resp. 16</b>	y	y	y	y	y	y

**Q2.10:** *Are you able to use the BIRO software now?*

The BIRO software, improved according the suggestions and the experiences collected during the training session in Kuwait, has been circulated within the small group of BIRO Partners for a second round of tests. Therefore, BIRO Partners are now highly experienced with the BIRO technology. The Coordinating Centre is going to be circulated among the whole EUBIROD consortium in due time before next meeting.

**Q2.11:** *Can you send us the BIRO report for your institution?*

A total of N=4 respondents out of N=16 answered they are able to send the BIRO report of their own Institutions.

**Q2.12:** *Can you send us the statistical objects produced from your report?*

A total of N=3 respondents out of N=16 answered that they are able to send the statistical objects to the central BIRO System

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?*

## •Before the meeting:

- ensure that software if fully tested, perhaps by partners who have not been involved in the development process because objective testing and

analysis cannot be completed by those so close to the system

- circulate more information about installation requirements so that Partners could be prepared before training sessions begins.
- offer on line help to the Partners to secure that the BIRO application works on the local datasets before the meeting.

•During the meeting:

- show the system from scratch in a database that runs properly from a collaborating partner
- define a better spreading of BIRO experts among all groups of trainees
- put in the schedule a specific session to discuss data sets and documents comparability
- split the training session in smaller parts with an associated milestone and then stop at the end of each part to summarize the work done and ensure that all participants have reached the milestone

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? Is it complete? How do you think it could be improved?*

The Coordinating Centre should provide a support system. It would be good if a special web site could be dedicated for this purpose. The web site could hold information like, "how you do it", FAQ (Frequently Asked Questions) sections, software requirements, setup requirements, documentation on database mapping, users and programmers guides with several degrees of detail (5, 50, 500 pages).

A very good approach would be to set up an interactive database, where users could submit problems and difficulties they encountered during their work with the BIRO software. In this way, an interactive help support website and a knowledge database can be built. This approach can be very effective and save a lot of time.

Developers should take into account that a lot of users work in very standardized network environments, managed by their employers IT-department and they usually don't have administrative privileges on their machines which are protected by a firewall.

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?*

Partners who have installed the latest version of BIROBox noticed that a considerable improvement has been realized since the training session in Kuwait thanks to the new setup routine. A further improvement could be an updater from a central server, so that project-members do not have to uninstall the old and reinstall the new version of the BIROBox. Some work still has to be done to trap and handle possible anomalies within the input dataset; if the application highlights an error, this should be log in a technical report and sent to the software developer for bug fixing.

## 5. Discussion: what we have learned

The BIRO approach has been extensively explained to EUBIROD Partners through multiple strategies: lectures at the first residential course, the BIRO Academy web site, the BIRO monograph. From the feedback received, it was all quite useful to allow partners be induced to BIRO and understand many aspects of the ongoing work. In the next session partners will need to explore in more detail the technical aspects related to the use of the BIRO technology.

Although the initial dissemination of BIRO can be considered to be successfully completed, more efforts should be dedicated to training.

The BIRO software aims at connecting multiple data sources, extracting and reshaping data before performing standardized statistical analysis. The system must overcome heterogeneous approaches in the organization of all partners, including structure of datasets, encoding, machines, languages and operating systems.

To deploy BIRO to the broader EUBIROD Consortium, the system must manage new scenarios. What worked for a small group of partners may not necessarily be adequate for a wider group. Although many efforts have been done to make the system as flexible and user-friendly as possible, the experience made at the training session in Kuwait demonstrated that more work is needed. New strategies may be required to facilitate usage of the system.

In this work, the developing team would need continuous feedback from partners. There is a need for active involvement in testing the system and reporting errors, to reproduce the conditions at the meeting, that allowed to better understand how to improve the system.

Some Partners felt discouraged by the problems emerged during the setup of the system, losing sight of a major achievement of the meeting: the fact that at least N=5 partners managed to obtain a statistical report, which demonstrates that the system can effectively work and provide results.

The first step of the BIRO Process, i.e. the interaction with local systems seems to be most difficult. However once the connection with the local system is established and data are imported successfully, the subsequent steps of the process flow quickly without requesting major efforts.

From the current position, the gap to be filled could be less than expected.

On the basis of the lesson learned, we have defined some action lines.

The Coordinating Centre has to:

- improve communication with Consortium Partners
- provide Partners with users' guides, tutorials, on-line help, demo of the software, i.e. as much information as possible focusing on the dissemination of the usage of BIRO product rather than its internal functioning
- embed in the BIRO Software more routines to highlight bugs to the developing team
- define clear procedures and tasks for every actor in the system
- reshape the training sessions by defining precise objectives and widening the

supporting team. More concrete working examples must be also used.

On the other hand, each Partner will be asked to play a more active role in the project and provide constructive feedback to improve project activities and all products.

## **6. Conclusions and perspectives**

Since the First residential course, the BIRO Software has been constantly revised and updated. Many of the suggestions received have been already taken into account, the remaining are in progress. Two versions have been delivered to BIRO Partners for revision. Feedback is encouraging.

Thanks to the new version of BIRO software and an improved help desk, more Partners, hopefully the whole Consortium, should be able to get the BIRO system up and running at own Institutions, improving local data processing.

The next EUBIROD meeting (Rome 19<sup>th</sup>-20<sup>th</sup> November) will offer the opportunity to assess the progress status and to discuss the statistical results obtained by each Partner locally. Hopefully, after that, all Partners will have gained proficiency about the usage of the BIRO software and the training phase will be on its way to be completed. The project is on schedule for the production of the first European Diabetes Report.

## Appendix A: Technical Requirements about Data Sources

This document describes how the data sources should be structured to be used within the EUBIROD Project.

The following five data elements are needed for the routinely functioning of BIRO software: merge table, activity table, population table diabetic population table, site header and profile information.

A small piece of the same tables should be used as test dataset to perform training activity on BIRO software during the 1<sup>st</sup> EUBIROD Annual Meeting in Kuwait.

Participants are kindly asked to bring a small test dataset of about 500-1000 patients in order to have the opportunity to test BIRO software on their own data. Participants who won't be able to bring their own dataset at the meeting, will be provided with a test dataset by the meeting organizer and will have the possibility to perform the training session on local machines already equipped with BIRO Software.

### Merge table

The merge table should have the following structure:

{patient\_ID, episode\_date, [data field], [data field],[data field],...}

where the couple patient\_ID and episode\_date represents the primary key of the table. In other words, each row of the merge table should represent a specific episode of a specific patient.

All possible [data fields] and their expected formats are listed in BIRO Common Dataset which is available at the results page of BIRO web site (<http://www.biro-project.eu/results.htm>).

For your convenience, a summary of BIRO Dataset is reported below:

Reference	BIRO Name	Parameter	Data Type	Enumerated Values/ Units of measurement
BIRO001	PAT_ID	Patient ID	String(12)	
BIRO002	DS_ID	Data Source ID	String(10)	
BIRO003	TYPE_DM	Type Of Diabetes	Enumerated	1 = Type 1 2 = Type 2 3 = Other types of Diabetes
BIRO004	SEX	Sex	Enumerated	1 = Male 2 = Female
BIRO005	DOB	Date of Birth	Date/Time	
BIRO006	DT_DIAG	Date of Diagnosis	Date/Time	
BIRO007	EPI_DATE	Episode Date	Date/Time	
BIRO008	SMOK_STAT	Smoking Status	Enumerated	1 = Current Smoker 2 = Non-Smoker 3 = Ex-smoker
BIRO009	CIGS_DAY	Cigarettes per day	Integer	
BIRO010	ALCOHOL	Alcohol Intake	Integer	g/week also accepted:g/day
BIRO011	WEIGHT	Weight	Real	Kg
BIRO012	HEIGHT	Height	Real	m; also accepted: cm
BIRO013	BMI	Body Mass Index	Real	
BIRO014	SBP	Systolic Blood Pressure	Integer	mmHg
BIRO015	DBP	Diastolic Blood Pressure	Integer	mmHg
BIRO016	HBA1C	HbA1c	Real	%
BIRO017	CREAT	Creatinine	Integer	µmol/l; also accepted: mg/dl
BIRO018	MA_TEST	Microalbumin	Enumerated	1 = MA Test Normal 2 = MA Test Abnormal 0 = No MA Test Recorded

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BIRO019	CHOL	Total Cholesterol	Integer	mmol/L ; also accepted: mg/dl
BIRO020	HDL	HDL	Integer	mmol/L; also accepted: mg/dl
BIRO021	TG	Triglycerides	Integer	mmol/L; also accepted: mg/dl
BIRO022	EYE_EXAM	Eye Examination	Enumerate d	1 = Yes 0 = No
BIRO023	RETINA	Retinopathy Status	Enumerate d	1 = No Retinopathy 2 = Background Retinopathy 3 = Referable Retinopathy
BIRO024	MACULA	Maculopathy Status	Enumerate d	1 = No Maculopathy 2 = Refedrabable Maculopathy
BIRO025	FOOT_EXAM	Foot Examination	Enumerate d	1 = Yes 0 = No
BIRO026	PULSES	Foot Pulses	Enumerate d	1 = Present 0 = Absent
BIRO027	FTSENS	Foot Sensation	Enumerate d	1 = Normal = Abnormal
BIRO028	ESRF	End Stage Renal Therapy	Enumerate d	1 = Yes 0 = No
BIRO029	DIALYSIS	Renal Dialysis	Enumerate d	1 = Yes 0 = No
BIRO030	TRANSPLANT	Renal Transplant	Enumerate d	1 = Yes 0 = No
BIRO031	STROKE	Stroke	Enumerate d	1 = Yes 0 = No
BIRO032	ULCER	Active Foot Ulcer	Enumerate d	1 = Yes 0 = No
BIRO033	MI	Myocardial Infarction	Enumerate d	1 = Yes 0 = No
BIRO034	LASER	Laser	Enumerate d	1 = Yes 0 = No
BIRO035	HYPERTENSION	Hypertension	Enumerate d	1 = Yes 0 = No
BIRO036	BLIND	Blindness	Enumerate d	1 = Yes 0 = No
BIRO037	AMPUT	Amputation	Enumerate d	1 = Yes 0 = No
BIRO038	HYPERT_MED	Antihypertensive Medication	Enumerate d	1 = Yes 0 = No
BIRO039	DRUG_THERAPY	Hypoglycemic Drug Therapy	Enumerate d	1 = Insulin Only 2 = Tablet Only 3 = Insulin and Tablets 4 = None (Diet Only)
BIRO040	ORAL_THERAPY	Oral Drug Therapy	Enumerate d	1 = Sulphonylureas 2 = Biguanides 3 = Glucosidase Inhibitors 4 = Glitazones 5 = Glinides
BIRO041	PUMP_THERAPY	Pump Therapy	Enumerate d	1 = Yes 0 = No
BIRO042	NASAL_THERAPY	Nasal Therapy	Enumerate d	1 = Yes 0 = No
BIRO043	INJECTIONS	Average Injections	Real	injections/day
BIRO044	SELF_MON	Self Monitoring	Enumerate d	1 = Urine 2 = Blood Glucose 3 = Both
BIRO045	EDUCATION	Diabetes Specific Education	Enumerate d	1 = Yes 0 = No
BIRO046	LIPID_THERAPY	Lipid Lowering Therapy	Enumerate d	1 = Yes 0 = No
BIRO047	ANTIPLATELET_THE	Anti-platelet	Enumerate	1 = Yes

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	RAPY	Therapy	d	0 = No
BIRO048	DMP_ENROL	Patient Enrolment in DMP for Diabetes	Enumerate d	1 = Yes 0 = No
BIRO049	ALC_STAT	Alcohol Status	Enumerate d	1 = Current Drinker 2 = Non-Drinker 3 = Ex-Drinker

The requested merge table has a very simple structure that cannot be easily found on real clinical databases, since they usually store much more information and this is distributed over many tables.

Probably each Participant would have to run some SQL queries on the local database in order to obtain a single big table with the desired format.

The merge table has to be produced not only for the meeting trial session but also for the routinely functioning of BIRO software within each local centre. With the occasion of the meeting, it would be sufficient to bring a short extract of the merge table containing about 500-1000 patient records.

Please note that:

- you don't have to include all BIRO fields in your merge table but only the fields that are routinely collected in your centre
- only patient ID, episode date and type of diabetes are mandatory
- you may use local field names for the merge table columns without changing them to BIRO names because they can be mapped through the BIRO Software
- you should check for each field that your local format is compliant with the BIRO format: i.e. you should check that you have a date if a date is expected for the corresponding BIRO field, you have an enumerated field where an enumerated field is expected and so on
- regarding numeric fields only the units of measurement written above can be used within the BIRO software. After the meeting, other units of measurements may be added
- regarding date fields you may use your own date format because it can be mapped through BIRO software
- regarding enumerated fields you don't have to change your enumerated values to comply with the specification above because they can be mapped through the BIRO software.

The merge table can be part of a database or a CSV file (comma separated value file).

If you choose the database option, please note that BIRO Software has been designed to work with any DBMS but only few have been tested (PostgreSQL, MySQL, MS SQL).

If you choose the CSV option please consider that only the following separators are allowed: “,” “;” “|”.

### Activity table

The activity table should contain information about the movement of patients with respect to the centre, i.e. dates of entry and exit from the centre and the related reasons (birth, diagnosis, transfer toward/from another centre, death, lost to follow-up).

The activity table should have the following structure:

{patient\_ID, start\_date, start\_reason, end\_date, end\_reason}

The couple Patient ID and start date represent the primary key of the table. Two different records with the same starting date related to the same patient are not allowed. The same patient may appear in more than one record because it is possible for a patient to have one continuous or several disjointed periods of activity based on their diagnosis dates, location of residence or follow up status.

Details about the requested fields are reported in the following table.

Reference	BIRO Name	Parameter	Data Type	Enumerated Values
BIRO001	PAT_ID	Patient ID	String(12)	
BIRO050	START_DATE	Start date	Date/Time	
BIRO051	START_REASON	Start reason	Enumerated	1 = birth 2 = diagnosis 3 = transfer from another centre
BIRO052	END_DATE	End date	Date/Time	
BIRO053	END_REASON	End reason	Enumerated	1 = death 2 = transfer towards another centre

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				3 = lost to follow up
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The activity table is very important for the correct calculation of indicators since it allows the statistical engine to skip the contribution of those patients not belonging to a centre within a specific time interval.

At the moment the activity table is not mandatory but it is highly recommended. At least the start date and the end date information should be provided. If this is not possible, the statistical engine will consider the date of diagnosis as start date.

As for the merge table, it is not necessary to map date fields and enumerated fields to a predefined format because this can be done using BIRO Software.

### Population table

The population table should contain information about the total population and mortality in the catchment area. In particular the number of persons (dead or alive) should be stratified on the basis of years, age bands and gender. An example of population table is reported below:

year	ageband	popM	popF	morM	morF
1997	1	19356	18289	8	14
1997	2	18623	17240	3	0
1997	3	18641	17562	5	1
1997	4	19819	18511	4	2

The age bandings are listed in deliverable D4.1 Data Dictionary and they are reported below for your convenience. The ranges are consistent with those defined in the EUCID Project:

Band ID	Lower range	Upper Range
1	0	14
2	15	24
3	25	34
4	35	44
5	45	54
6	55	64
7	65	74
8	75	84
9	85	none

The population table should be submitted in form of CSV file.

### Diabetic population table

The diabetic population table should refer only to diabetic patients within the catchment area. The expected structure is the following:

year	ageband	typedm	diabM	diabF
1997	1	1	100	90
1997	2	1	201	300
1997	3	1	343	250
1997	4	1	432	300

The diabetic population table should be submitted in form of csv file. This is not a mandatory requirement. If not present the statistical engine will reconstruct it starting from the merge table.

### Site header and profile information

Partners will be asked to fill a form with the following static contact details regarding own centre:

Ref.	Field Name	Parameter	Data Type	Enumerated Codes
BIRO101	DS_COUNTRY	Country of Origin	String(25)	
BIRO102	DS_TYPE	Data Source Type	Enumerated	1 = GP 2 = Hospital Clinic (Internal Medicine) 3 = Hospital Clinic (Diabetes)

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				4 = Regional Shared-data Register 5 = Regional Primary Care Project 6 = Disease Management Programme 7 = Hospital Discharge Information 8 = Insurance Programme 9 = Retinal Screening Programme 10 = Diabetes Specialist Nurse Clinic 11 = National Data – Complete 12 = National Data – Sample 13 = Regional Data – Sample
BIRO103	DS_NAME	Data Source Name	String(25)	
BIRO106	DS_WEBSITE	Website Address	String(50)	
BIRO107	DS_ADDRESS_1	Mailing Address Field 1	String(25)	
BIRO108	DS_ADDRESS_2	Mailing Address Field 2	String(25)	
BIRO109	DS_ADDRESS_3	Mailing Address Field 3	String(25)	
BIRO110	DS_ADDRESS_4	Mailing Address Field 4	String(25)	
BIRO111	DS_POST_CODE	Post Code of Data Source	String(25)	
BIRO112	DS_C_CONTACT	Clinical Contact	String(25)	
BIRO113	DS_C_EMAIL	Clinical Contact Email Address	String(50)	
BIRO114	DS_T_CONTACT	Technical Contact	String(25)	
BIRO115	DS_T_EMAIL	Technical Contact Email Address	String(50)	

Partners will be also asked to fill a form with the following static information regarding the centre profile:

Ref.	Field Name	Parameter	Data Type	Enumerated Codes
BIRO104	DS_DENOM	Data Source Denominator	Integer	
BIRO105	DS_AREA	Geographical Area	Integer	
BIRO116	DS_BEDS	Hospital Beds	Integer	
BIRO117	DS_PHYSICIANS	Physicians	Integer	
BIRO118	DS_DIABETOLOGISTS	Diabetes Specialist Consultants	Integer	
BIRO119	DS_DOCTORS	Doctors	Integer	
BIRO120	DS_DSN	Specialist Diabetes Nurses	Integer	
BIRO121	DS_PROGS	Disease Management Programmes	Integer	
BIRO122	DS_DMP_PHYSICIANS	Physicians Offering DMP's for Diabetes	Integer	

## Appendix B: Questionnaire about data sources availability

Institution Name:  
 Technical Contact Person  
 Who may be contacted in your institution concerning technical issues?  
 Name:  
 Email:  
 Phone:

Please answer the following questions concerning data sources availability at the 1<sup>st</sup> EUBIROD Annual meeting in Kuwait

<p><b>a) Will your Institution be able to provide its own dataset?</b>  <input type="checkbox"/> yes, I would prefer to do training activity on my own dataset  <input type="checkbox"/> No, I would prefer to do training activity on provided test dataset                  General Comment:</p>
<p><b>b) Will you bring your own notebook to test BIRO Software?</b>  <input type="checkbox"/> yes  <input type="checkbox"/> no                  General Comment:</p>
<p><b>c) In case you bring a notebook, which OS is installed on it?</b>  <input type="checkbox"/> Windows  <input type="checkbox"/> Linux                  General Comment:</p>
<p><b>d) Will your Institution be able to bring the merge table, in which format?</b>  <input type="checkbox"/> yes, as database:  <input type="checkbox"/> yes, as CSV file  <input type="checkbox"/> yes, with a different format:  <input type="checkbox"/> no                  General Comment:</p>
<p><b>e) Will your Institution be able to bring the activity table, in which format?</b>  <input type="checkbox"/> yes, as database:  <input type="checkbox"/> yes, as CSV file  <input type="checkbox"/> yes, with a different format:  <input type="checkbox"/> no                  General Comment:</p>
<p><b>f) Will your Institution be able to provide the population table?</b>  <input type="checkbox"/> yes, as CSV file  <input type="checkbox"/> yes, with a different format:  <input type="checkbox"/> no                  General Comment:</p>
<p><b>g) Will your Institution be able to provide the diabetic population table?</b>  <input type="checkbox"/> yes, as CSV file  <input type="checkbox"/> yes, with a different format:  <input type="checkbox"/> no                  General Comment:</p>
<p><b>g) Will your Institution be able to provide information on site profile?</b>  <input type="checkbox"/> yes  <input type="checkbox"/> no                  General Comment:</p>

## Appendix C: BIROBox Setup Guide

### REQUIRED SOFTWARE

In order to run BIROBox you have to install some prerequisite software:

- 1.If not already present, please install R statistical software (version 2.8.0 recommended).You can download it from <http://www.r-project.org/>
- 2.if not already present, please install Java. You can download the latest version of Java SE (JDK) from <http://java.sun.com/javase/downloads/index.jsp>. All Java versions since 1.6.0\_6 are guaranteed to work.
- 3.If not already present please install MiKTeX 2.7. You can download it from <http://miktex.org>.
- 4.If not already present, please download and install Apache Ant from <http://ant.apache.org/> . All versions since 1.6.5 are guaranteed to work

### BIROBox SETUP

The BIROBox setup file is a self extracting file. You just have to double click on BIROBox.exe and choose the folder where you want to install the BIRO Environment.

### ENVIRONMENT SETTINGS

- 1.Create the R\_HOME environment variable  
R\_HOME = <R setup folder>  
(as example: R\_HOME C:\R\R-2.8.0)
- 2.Set the JAVA\_HOME environment variable  
JAVA\_HOME = <Java setup folder>  
(as example: JAVA\_HOME C:\Programs\Java\jdk1.6.0\_6)
- 3.Set the TOMCAT2\_HOME environment variable (\*)  
TOMCAT2\_HOME = <BIRO setup folder>\ BIRO\software\\_cs\\_apache-tomcat-5.5-2
- 4.Set the AXIS2\_HOME environment variable (\*)  
AXIS2\_HOME = <BIRO setup folder>\ BIRO\software\\_cs\\_axis2-1.4
- 5.set the ANT\_HOME environment variable  
ANT\_HOME = <ANT setup folder>
- 6.Update your PATH environment variable by adding the ANT\_HOME at the end of it  
PATH = [...];ANT\_HOME\bin (please, don't forget ";")
- 7.Update your PATH environment variable by adding the R\_HOME at the end of it  
PATH = [...];<R setup folder> (please, don't forget ";")
- 8.Copy the file <BIRO setup folder>\ BIRO\software\\_cs\\_resources\bcprov-jdk16-141.jar to your JAVA\_HOME\jre\lib\ext folder
- 9.Copy the 2 jar files (local\_policy.jar and US\_export\_policy.jar) from <BIRO setup folder>\ BIRO\software\\_cs\\_resources\jce\_policy-6.zip in \$JAVA\_HOME\jre\lib\security and overwrite existing policies.
- 10.Add the following entry to your \$JAVA\_HOME\jre\lib\security\java.security file:  
security.provider.N+1=org.bouncycastle.jce.provider.BouncyCastleProvider  
where N is the highest number available in the list of SecurityProviders

(\*) optional step: it is only needed if you want to test the BIRO Central Server on your own machine.

**HOW TO RUN BIROBox**

Once you have installed the BIRO Environment, you can simply run BIRO Box by double clicking on runBIROBoxGUI.bat

## Appendix D: Training Questionnaire

### EUBIROD Training Questionnaire

#### 1. Lectures

**Q1.1:** What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?

**Q1.2:** Is there any topic that you want to be covered in more detail at next meetings?

**Q1.3:** Can you suggest any topic that was not covered?

**Q1.4:** Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?

#### 2. Training

**Q2.1:** Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?

**Q2.2:** Was the procedure used for training appropriate? What worked? What didn't work?

**Q2.3:** Was the introductory description of the usage of the software appropriate?

**Q2.4:** Did you work on your notebook or on a computer provided by the organization?

**Q2.5:** Were there any problems with basic hardware/software installed or required to conduct training that you can report?

**Q2.6:** Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?

**Q2.7:** Were there any particular problems using the database that you can report?

**Q2.8:** Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.

**Q2.9:** At the end of the session, did you succeed in:

- a) running the BIRO software (using the BIROBox)
- b) mapping data from your test dataset to the BIRO definitions
- c) exporting data in BIRO XML format
- d) loading data on the BIRO Postgres database
- e) running the statistical engine
- f) producing the final BIRO report

**Q2.10:** Are you able to use the BIRO software now?

**Q2.11:** Can you send us the BIRO report for your institution?

**Q2.12:** Can you send us the statistical objects produced from your report?

**Q2.13:** Any suggestions on how to improve the organization of the next training sessions

#### 3. Training material

**Q3.1:** What do you think about the training material currently available? Is it clear enough? is it complete? How do you think it could be improved?

**Q3.2:** What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?

## Appendix E: Results of Training Questionnaires

### EUBIROD Training Questionnaire n°1

#### 1. Lectures

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?*

**A1.1:** Interesting yes. Not so useful for me as one of the BIRO partners that knew most of the content from before

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?*

**A1.2:** Will have to with development. Also maybe how all elements of technology are linked together

**Q1.3:** *Can you suggest any topic that was not covered?*

**A1.3:** No (too long time has passed since meeting, probably easier for new partners to say)

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?*

**A1.4:** Participation is always good. How to organize and make it fruitful is difficult.

#### 2. Training

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?*

**A2.1:** Facilities ok, too much time spent waiting for support or discussions with experts.

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

**A2.2:** More assistance required – but that rests on the degree of success for the software testing. When almost nobody made everything work properly, everyone felt they were kept waiting

**Q2.3:** *Was the introductory description of the usage of the software appropriate?*

**A2.3:** I think so, the problem was function not introduction I think (this is secondary info, I was not there at this time)

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?*

**A2.4:** Notebook

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?*

**A2.5:** To make this work on our dataset was difficult

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?*

**A2.6:** Own data

**Q2.7:** *Were there any particular problems using the database that you can report?*

**A2.7:** As mentioned above, the database itself was not (I think) the problem

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.*

**A2.8:**

**Q2.9:** *At the end of the session, did you succeed in:*

a) *running the BIRO software (using the BIROBox)* **A2.9a:**

b) *mapping data from your test dataset to the BIRO definitions* **A2.9b:**

c) *exporting data in BIRO XML format* **A2.9c:**

d) *loading data on the BIRO Postgres database* **A2.9d:**

e) *running the statistical engine* **A2.9e:**

f) *producing the final BIRO report* **A2.9f:**

**Q2.10:** *Are you able to use the BIRO software now?*

**A2.10:** I don't think we are using it now

**Q2.11:** *Can you send us the BIRO report for your institution?*

**A2.11:** Privacy issue still under consideration

**Q2.12:** *Can you send us the statistical objects produced from your report?*

**A2.12:**

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?*

**A2.13:** Better testing of software solutions beforehand

#### 3. Training material

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? Is it complete? How do you think it could be improved?*

**A3.1:**

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?*

**A3.2:**

## EUBIROD Training Questionnaire n°2

### 1. Lectures

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?* **A1.1:**

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?* **A1.2:**

**Q1.3:** *Can you suggest any topic that was not covered?* **A1.3:**

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?* **A1.4:** I have made several suggestions in the answers below.

### 2. Training

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?*

**A2.1:** The facilities were fine. Read Q2.5 for answer regarding the software part.

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

**A2.2:** I can only answer for the technical part, and that was total chaos. Read below for further explanation.

**Q2.3:** *Was the introductory description of the usage of the software appropriate?*

**A2.3:** The description was fine; it was the actual usage that was problematic.

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?* **A2.4:** My own notebook.

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?*

**A2.5:** The only issue as I see it was that all partners were downloading the required software at the same time. This led to poor download speeds for everyone because the wireless network was overloaded. I would suggest cabled network for the next meeting, or if that is not possible then at least provide a set of cd's to install from.

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?* **A2.6:** Data set provided by the Coordinating Centre.

**Q2.7:** *Were there any particular problems using the database that you can report?*

**A2.7:** Yes, the standard installation of Postgres did not work with the BIRO software (some issues with the database name I think).

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.*

**A2.8:** It's been a while since the training sessions, so the details elude me. However, I remember installing all the required software (Postgres, R, etc). That part went fairly well. The remainder of the time was spent tweaking out several different problems to get the BIRO box to run properly and to produce a report. I'm sorry, but I don't remember the details about the problems.

**Q2.9:** *At the end of the session, did you succeed in:*

a) *running the BIRO software (using the BIROBox)* **A2.9a:** Yes

b) *mapping data from your test dataset to the BIRO definitions* **A2.9b:** From test set provided, yes.

c) *exporting data in BIRO XML format* **A2.9c:** Yes

d) *loading data on the BIRO Postgres database* **A2.9d:** Yes

e) *running the statistical engine* **A2.9e:** Yes

f) *producing the final BIRO report* **A2.9f:** Yes

**Q2.10:** *Are you able to use the BIRO software now?* **A2.10:** Unknown, we have not attempted to use it.

**Q2.11:** *Can you send us the BIRO report for your institution?* **A2.11:** No, we have not produced a report yet.

**Q2.12:** *Can you send us the statistical objects produced from your report?* **A2.12:** No, we haven't produced a report yet.

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?*

**A2.13:** The BIRO experts were all gathered at one table (group). Perhaps it would be better if they were spread amongst the groups so that the groups know who to contact when problems arise. Also it would be beneficial if participants could get information of what software the installation requires so that they can install that well in time for the training sessions to begin.

### 3. Training material

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? Is it complete? How do you think it could be improved?* **A3.1:** We have not reviewed the training material currently available.

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?* **A3.2:** We have not installed the latest version.

### EUBIROD Training Questionnaire n°3

#### 1. Lectures

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?*

**A1.1:** This plenary session, in a secluded exotic location, was a very clear overview for the EUBIROD consortium members of the activities of BIRO and the start of the practical activities of EUBIROD. The BIRO approach was clear to everyone after the training and the hands on training of the system was very useful but also frustrating.

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?*

**A1.2:** The topic of use of the data once the system of EUBIROD is running, apart from the standard reports.

**Q1.3:** *Can you suggest any topic that was not covered?* **A1.3:** See Q1.2

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?*

**A1.4:** Detailed experience of one of the members who succeeded in compiling the data

#### 2. Training

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?*

**A2.1:** All these fields were covered appropriately

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

**A2.2:** The procedure was fine, but the software was still in a version where there were too many problems.

**Q2.3:** *Was the introductory description of the usage of the software appropriate?*

**A2.3:** Yes

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?*

**A2.4:** notebook

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?*

**A2.5:** There were profound problems with windows Vista and the software.

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?*

**A2.6:** Local extracted data in Excel and SPSS format

**Q2.7:** *Were there any particular problems using the database that you can report?*

**A2.7:** Importing data from the CSV file was a problem for date fields and several yes/no fields

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.*

**A2.8:** After giving two presentations I tried to get the data of the Hoorn database into the system installed from BIRO BOX. After two half days of trying we almost succeeded in exporting the data. The whole group worked together in a proper way and the support from the ICT people of EUBIROD was perfect, but the system was just not sufficiently stable.

**Q2.9:** *At the end of the session, did you succeed in:*

a) *running the BIRO software (using the BIROBox)* **A2.9a:** Yes

b) *mapping data from your test dataset to the BIRO definitions* **A2.9b:** Partly

c) *exporting data in BIRO XML format* **A2.9c:** No

d) *loading data on the BIRO Postgres database* **A2.9d:** No

e) *running the statistical engine* **A2.9e:** No

f) *producing the final BIRO report* **A2.9f:** No

**Q2.10:** *Are you able to use the BIRO software now?*

**A2.10:** Still in the process of installing the updated software

**Q2.11:** *Can you send us the BIRO report for your institution?*

**A2.11:** Not yet

**Q2.12:** *Can you send us the statistical objects produced from your report?*

**A2.12:** Not yet

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?*

**A2.13:** Show the system from scratch in a database that runs properly from a collaborating partner

#### 3. Training material

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? Is it complete? How do you think it could be improved?*

**A3.1:** Especially the mapping of the databases and the problems arising there should be documented more extensively.

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?*

**A3.2:** Still in the process of installing the latest version of BIROBox, so cannot answer, but are very confident that the bugs that were found during the Kuwait meeting are being fixed.

## EUBIROD Training Questionnaire n°4

### 1. Lectures

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?*

**A1.1:** In my opinion, the lectures were interesting and useful.

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?*

**A1.2:** No, the topics of the previous meeting were understandable enough.

**Q1.3:** *Can you suggest any topic that was not covered?*

**A1.3:** Every necessary topics were covered.

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?*

**A1.4:** I think the format of the session is adequate.

### 2. Training

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?*

**A2.1:** Yes, the facilities were appropriate and all necessary softwares were installed.

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

**A2.2:** There were some minor errors (error messages), but the help of the staff was appropriate.

**Q2.3:** *Was the introductory description of the usage of the software appropriate?*

**A2.3:** Yes, it was.

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?*

**A2.4:** We worked on a computer, which was provided by the organization.

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?*

**A2.5:** There were no problems.

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?*

**A2.6:** We used the test dataset of the Coordinating Centre.

**Q2.7:** *Were there any particular problems using the database that you can report?*

**A2.7:** No.

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.*

**A2.8:**

**Q2.9:** *At the end of the session, did you succeed in:*

a) *running the BIRO software (using the BIROBox)* **A2.9a:** Yes, the software is userfriendly.

b) *mapping data from your test dataset to the BIRO definitions* **A2.9b:** Yes, the mapping was successful.

c) *exporting data in BIRO XML format* **A2.9c:** Yes, it worked.

d) *loading data on the BIRO Postgres database* **A2.9d:** Yes, it worked.

e) *running the statistical engine* **A2.9e:** Yes, it was successful.

f) *producing the final BIRO report* **A2.9f:** Yes, we completed.

**Q2.10:** *Are you able to use the BIRO software now?*

**A2.10:** Yes, I can use now the BIRO software.

**Q2.11:** *Can you send us the BIRO report for your institution?*

**A2.11:** I am able to send our report.

**Q2.12:** *Can you send us the statistical objects produced from your report?*

**A2.12:** I am able to send statistical objects.

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?*

**A2.13:** No, everything was fine.

### 3. Training material

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? It is complete? How do you think it could be improved?*

**A3.1:** In my opinion it is clear enough.

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?*

**A3.2:** Where can I find the latest version?

## EUBIROD Training Questionnaire n°5

### 1. Lectures

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?*

**A1.1:** Yes, it was interesting and useful to understand.

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?*

**A1.2:** No

**Q1.3:** *Can you suggest any topic that was not covered?*

**A1.3:** No

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?*

**A1.4:** No, I think it was very useful that each of us could work with the program in Kuwait.

### 2. Training

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?*

**A2.1:** We had some problems by using the software, but that was absolutely not your fault!!

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

**A2.2:** None of it worked for us, but again it was absolutely not your fault.

**Q2.3:** *Was the introductory description of the usage of the software appropriate?*

**A2.3:** Unfortunately there had been some kind of mistake, so we didn't get the mails with the in which you describe what we had to do before the meeting.

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?*

**A2.4:** Notebook

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?*

**A2.5:** See Q 2.3

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?*

**A2.6:** We didn't work on anything at all

**Q2.7:** *Were there any particular problems using the database that you can report?*

**A2.7:** Not any problems that is connected to your software.

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.*

**A2.8:**

**Q2.9:** *At the end of the session, did you succeed in:*

a)running the BIRO software (using the BIROBox) **A2.9a:** No

b)mapping data from your test dataset to the BIRO definitions **A2.9b:** No

c)exporting data in BIRO XML format **A2.9c:** No

d)loading data on the BIRO Postgres database **A2.9d:** No

e)running the statistical engine **A2.9e:** No

f)producing the final BIRO report **A2.9f:** No

**Q2.10:** *Are you able to use the BIRO software now?*

**A2.10:**

**Q2.11:** *Can you send us the BIRO report for your institution?*

**A2.11:**

**Q2.12:** *Can you send us the statistical objects produced from your report?*

**A2.12:**

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?*

**A2.13:**

### 3. Training material

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? Is it complete? How do you think it could be improved?*

**A3.1:**

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?*

**A3.2:**

## EUBIROD Training Questionnaire n°6

### 1. Lectures

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?*

**A1.1:** I understand that you need to have some lectures and backgrounders on the topic. In my opinion you could reduce a lot of the lectures and more focus on the technical and training parts

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?* **A1.2:** We would like to have a better understanding about what softwares that are needed for our application to work properly

**Q1.3:** *Can you suggest any topic that was not covered?* **A1.3:** Open source softwares for this project

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?* **A1.4:** More practical exercises on site using the application on our own dataset

### 2. Training

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?* **A2.1:** please see above

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

**A2.2:** In generally fine. It's good to have hands on sessions. However, we wanted more information on how to install the BIRO-software properly, and how to use it on our PC

**Q2.3:** *Was the introductory description of the usage of the software appropriate?* **A2.3:** please see above

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?* **A2.4:** own notebook

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?* **A2.5:** The installation process of the BIRO-software was hard to follow. We would appreciate a more standardized, set-up package application installation routine for the BIRO-software. It's very difficult when you manually need to download software's and have to set environment variables in the notebook. More instructions and basics would be appreciated

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?* **A2.6:** We worked on own data

**Q2.7:** *Were there any particular problems using the database that you can report?*

**A2.7:** We had problems to get the BIRO application to fit our own dataset completely and properly. It worked for some parts, but not on all

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.* **A2.8:**

**Q2.9:** *At the end of the session, did you succeed in:*

a) *running the BIRO software (using the BIROBox)* **A2.9a:** some parts worked

b) *mapping data from your test dataset to the BIRO definitions* **A2.9b:** worked

c) *exporting data in BIRO XML format* **A2.9c:**

d) *loading data on the BIRO Postgres database* **A2.9d:** no

e) *running the statistical engine* **A2.9e:** some parts

f) *producing the final BIRO report* **A2.9f:** no

**Q2.10:** *Are you able to use the BIRO software now?* **A2.10:** no

**Q2.11:** *Can you send us the BIRO report for your institution?* **A2.11:** no

**Q2.12:** *Can you send us the statistical objects produced from your report?* **A2.12:** no

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?* **A2.13:** The next training session could be better prepared by careful guidance over the internet to secure that the BIRO application works on the local datasets before the meeting. The planning should still give time for practical training sessions on your own.

### 3. Training material

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? it is complete? How do you think it could be improved?*

**A3.1:** One critical aspect to get this to work properly is to have a good support system. I think it would be good if you in the future could dedicate a special web site for this purpose. The web site could hold information like, "how you do it", FAQ (Frequently Asked Questions) sections, what software's you need, what settings you need to do etc. A very good approach would be if you could set up an interactive database, where users could submit problems and difficulties they encountered during their work with the BIRO software. In this way, you build an interactive help support website and you create a kind of knowledge database. The developers also have an idea what they should improve. This approach is very effective and it saves a lot of time. I think it's critical to get this help system to work and that you can provide the users with good information, on a lot of topics. Another important issue is that a lot of users, like ourselves, are sitting behind firewalls and in very standardized network environments managed by their employers IT-department.

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?* **A3.2:** If it is a new version published after the meeting in Kuwait, we haven't seen it. Again, the communication need to more explicit and more individualized to get through.

## EUBIROD Training Questionnaire n°7

### 1. Lectures

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?*

**A1.1:** Ok, some may be a bit too political and not completely adjusted to the topic of the meeting but in general ok

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?*

**A1.2:** More discussion on the indicator reproducibility/comparability, as well as the denominator characteristics technical training, functioning and simplified BIROBox. At the time of the first course, some technical problems were detected, rendering the workshop even more useful as direct feedback led to improved technologies

**Q1.3:** *Can you suggest any topic that was not covered?*

**A1.3:** one might need even more time for technical aspects. More details before the meeting in order to arrive even better prepared

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?*

**A1.4:** NO, size was more than sufficient

### 2. Training

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?*

**A2.1:** Facilities ok, support ok, organisation ok!

Children's diseases were discovered. The tool box should be easier in order to allow in the long run correct benchmarking

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

**A2.2:** In general as expected in this phase of the study

**Q2.3:** *Was the introductory description of the usage of the software appropriate?*

**A2.3:** not sufficient for non IT people

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?*

**A2.4:** notebook

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?*

**A2.5:** no but I did need a lot of help to adjust the environment

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?*

**A2.6:** provided by the coordinating centre, but not functioning (yet)

**Q2.7:** *Were there any particular problems using the database that you can report?*

**A2.7:** gender problem in the encoding, solvable

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.*

**A2.8:** positive. Each step forward is one step.

It seems not yet ready to be applied in all programs, nor data sets. But some did manage. This indicates that the problems can be addressed and resolved. In a second phase of course the technical problems should be solved. Then the very precise definition of core indicators and their definitions as well as the definitions of the data sources should be prepared, to allow reliable comparison

**Q2.9:** *At the end of the session, did you succeed in:*

a) *running the BIRO software (using the BIROBox)* **A2.9a:** No gender item in the program. Not solved

b) *mapping data from your test dataset to the BIRO definitions* **A2.9b:** no, see above

c) *exporting data in BIRO XML format* **A2.9c:** yes

d) *loading data on the BIRO Postgres database* **A2.9d:** yes

e) *running the statistical engine* **A2.9e:** yes, half way

f) *producing the final BIRO report* **A2.9f:**

**Q2.10:** *Are you able to use the BIRO software now?*

**A2.10:** no, no further update on the corrected BIROBox has been made available despite our asking (Valery Bocquet)

**Q2.11:** *Can you send us the BIRO report for your institution?* **A2.11:** No see above

**Q2.12:** *Can you send us the statistical objects produced from your report?* **A2.12:** no see above

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?*

**A2.13:** provide corrected methods, discuss data sets and documents comparability

### 3. Training material

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? Is it complete? How do you think it could be improved?* **A3.1:** simplify

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?* **A3.2:** not yet ready, but hopefully within shortly

## EUBIROD Training Questionnaire n°8

### 1. Lectures

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?*

**A1.1:** They were interesting and useful to understand the BIRO approach

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?*

**A1.2:** NO

**Q1.3:** *Can you suggest any topic that was not covered?*

**A1.3:** NO

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?*

**A1.4:** To be the same format.

### 2. Training

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?*

**A2.1:** Yes

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

**A2.2:** It was appropriate

**Q2.3:** *Was the introductory description of the usage of the software appropriate?*

**A2.3:** yes it was

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?*

**A2.4:** Work was on my own notebook

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?*

**A2.5:** No

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?*

**A2.6:** Extracted from a local database of our institution

**Q2.7:** *Were there any particular problems using the database that you can report?*

**A2.7:** Problems due to database errors and lack of EU standards in EHCR in local database of local institution

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.*

**A2.8:**

**Q2.9:** *At the end of the session, did you succeed in:*

a) *running the BIRO software (using the BIROBox)* **A2.9a:** Yes

b) *mapping data from your test dataset to the BIRO definitions* **A2.9b:** Yes

c) *exporting data in BIRO XML format* **A2.9c:** Yes

d) *loading data on the BIRO Postgres database* **A2.9d:** loading data on the BIRO MySQL database

e) *running the statistical engine* **A2.9e:** Yes

f) *producing the final BIRO report* **A2.9f:** Yes

**Q2.10:** *Are you able to use the BIRO software now?*

**A2.10:** Yes

**Q2.11:** *Can you send us the BIRO report for your institution?*

**A2.11:** Yes, for the indicators that can be found in the local database

**Q2.12:** *Can you send us the statistical objects produced from your report?*

**A2.12:** Yes

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?*

**A2.13:** No

### 3. Training material

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? it is complete? How do you think it could be improved?*

**A3.1:** Clear enough

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?*

**A3.2:** Yes it was checked the BIROBox GUI version 4

## EUBIROD Training Questionnaire n°9

### 1. Lectures

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?*

**A1.1:** Coming from a technical background I would say that the lectures were interesting.

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?*

**A1.2:** indicators and derivatives is what interests me most.

**Q1.3:** *Can you suggest any topic that was not covered?*

**A1.3:** I do not have a medical background I would not know.

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?*

**A1.4:** interactive panel is fine.

### 2. Training

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?*

**A2.1:** I would say that the venue and facilities were appropriate but software varied from one pc installation to another as it depends on how the os is installed in the first place.

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

**A2.2:** I would have preferred to have moved pace by pace all together rather than having sporadic groups all working on their own thus we would have left Kuwait with all participating countries at a particular point in the cycle and continue from there next time round.

**Q2.3:** *Was the introductory description of the usage of the software appropriate?*

**A2.3:** I do not remember.

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?*

**A2.4:** pc provided by the organization when the software worked.

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?*

**A2.5:** As reported earlier the hardware/software experienced os problems.

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?*

**A2.6:** extracted from a local database of our institution

**Q2.7:** *Were there any particular problems using the database that you can report?*

**A2.7:** No not really just that the mappings need more detailed explanation as well as detail on criteria that it will accept.

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.*

**A2.8:**

**Q2.9:** *At the end of the session, did you succeed in:*

a) *running the BIRO software (using the BIROBox)* **A2.9a:** Yes

b) *mapping data from your test dataset to the BIRO definitions* **A2.9b:** Yes not without tweaking data

c) *exporting data in BIRO XML format* **A2.9c:** Yes not without tweaking/help from colleagues

d) *loading data on the BIRO Postgres database* **A2.9d:** Yes not without tweaking/help from colleagues

e) *running the statistical engine* **A2.9e:** Yes not without tweaking/help from colleagues

f) *producing the final BIRO report* **A2.9f:** Yes not without tweaking/help from colleagues

**Q2.10:** *Are you able to use the BIRO software now?*

**A2.10:** Yes till step one (mapping) and than it does not go further than that

**Q2.11:** *Can you send us the BIRO report for your institution?*

**A2.11:** the results are empty

**Q2.12:** *Can you send us the statistical objects produced from your report?*

**A2.12:** no

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?*

**A2.13:** step by step in one group so that we will know were each and every participant is and where to continue next from the next time round.

### 3. Training material

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? it is complete? How do you think it could be improved?*

**A3.1:** I did not have the time to go through it sorry.

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?*

**A3.2:** I did not have the time to go through it sorry.

## EUBIROD Training Questionnaire n°10

### 1. Lectures

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?*

**A1.1:** I found them interesting and informative, very worthwhile.

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?*

**A1.2:** More information on the software setup procedure and options.

**Q1.3:** *Can you suggest any topic that was not covered?* **A1.3:** No

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?*

**A1.4:** No, I liked the approach used previously. Improved access to experienced BIROBox developers/administrators would help considerably.

### 2. Training

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?*

**A2.1:** Yes, everything was of a very high standard and well organised.

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

**A2.2:** Training was good but it was a pity we couldn't have spent more time using the software because setting up and getting the software running took so long.

**Q2.3:** *Was the introductory description of the usage of the software appropriate?* **A2.3:** Yes

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?*

**A2.4:** Computer provided by the organisation.

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?*

**A2.5:** The basic software installations were straightforward. There were too many of them though, all the individual applications and utilities need to be bundled into one installation (as much as possible), when it is ready.

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?* **A2.6:** Data provided by the Coordinating Centre.

**Q2.7:** *Were there any particular problems using the database that you can report?*

**A2.7:** The build would only work with Postgres, which is fine. We should not be limited to this one database option though.

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.*

**A2.8:** Installing and setting up took some time because of all the different packages and programs involved. I eventually got it working but had to put some of the commands through manually. There were far too many glitches and problems when running the software. It did not work seamlessly, often failing between processes, meaning the administrators had to intervene to allow any jobs running to finish. I managed to generate the report in the end, it was not a straightforward process though. At the same time, I expect a lot of useful lessons were learned by the developers.

**Q2.9:** *At the end of the session, did you succeed in:*

- a) *running the BIRO software (using the BIROBox)* **A2.9a:** Yes
- b) *mapping data from your test dataset to the BIRO definitions* **A2.9b:** Yes
- c) *exporting data in BIRO XML format* **A2.9c:** Yes
- d) *loading data on the BIRO Postgres database* **A2.9d:** Yes
- e) *running the statistical engine* **A2.9e:** Yes
- f) *producing the final BIRO report* **A2.9f:** Yes

**Q2.10:** *Are you able to use the BIRO software now?*

**A2.10:** Yes but I have not tried again recently. I am waiting for a stable version before I set up BIROBox on a machine in our own institution.

**Q2.11:** *Can you send us the BIRO report for your institution?* **A2.11:** No

**Q2.12:** *Can you send us the statistical objects produced from your report?* **A2.12:** No

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?*

**A2.13:** Have a stable, working version of BIROBox available.

### 3. Training material

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? It is complete? How do you think it could be improved?* **A3.1:** The guidelines and material made available are of a good standard.

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?* **A3.2:** I think it has great potential; some excellent work has been done to date. I have not checked any version since the training in Kuwait. As soon as a proven working version is available, I will get it up and running. I will have to use it more before I can suggest improvements.

## EUBIROD Training Questionnaire n°11

### 1. Lectures

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?*

**A1.1:** The lectures were very interesting and useful

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?*

**A1.2:** None

**Q1.3:** *Can you suggest any topic that was not covered?*

**A1.3:** No

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?*

**A1.4:** Whilst the lecture is being delivered, I feel it would be beneficial to be doing the actual practical on our computers following the instructions and seeing it presented at the same time.

### 2. Training

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?*

**A2.1:** Venue very good with excellent facilities. The software was available

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

**A2.2:** People were available to help out

**Q2.3:** *Was the introductory description of the usage of the software appropriate?*

**A2.3:** Cannot remember: I feel this questionnaire should have been completed whilst we were in Kuwait at the time of the meeting.

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?*

**A2.4:** On my own notebook

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?*

**A2.5:** There were some problems with my Vista windows which were sorted out by the organisers.

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?*

**A2.6:** Database from my institution

**Q2.7:** *Were there any particular problems using the database that you can report?*

**A2.7:** None

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.*

**A2.8:** Personally I found the work very hard because I am a DSN and our IT person was not able to come at the last minute because of a technicality ref. her visa. Nevertheless, all the IT people were helping me out at every step of the way. I know if our IT person was there we would have been able to do much better.

**Q2.9:** *At the end of the session, did you succeed in:*

a) *running the BIRO software (using the BIROBox)* **A2.9a:** Yes

b) *mapping data from your test dataset to the BIRO definitions* **A2.9b:** Yes

c) *exporting data in BIRO XML format* **A2.9c:** No

d) *loading data on the BIRO Postgres database* **A2.9d:** No

e) *running the statistical engine* **A2.9e:** No

f) *producing the final BIRO report* **A2.9f:** No

**Q2.10:** *Are you able to use the BIRO software now?*

**A:** Our IT team member says yes

**Q2.11:** *Can you send us the BIRO report for your institution?*

**A:** No

**Q2.12:** *Can you send us the statistical objects produced from your report?*

**A:** No

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?*

**A:** This is clearly a meeting where the presence of the IT people is a MUST

### 3. Training material

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? it is complete? How do you think it could be improved?*

**A:** They are clear

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?*

**A:** It is alright.

## EUBIROD Training Questionnaire n°12

### 1. Lectures

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?*

**A1.1:** As we have been involved since BIRO, the content was familiar but clinically interesting.

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?*

**A1.2:** Proposed presentation of results with working prototype website.

**Q1.3:** *Can you suggest any topic that was not covered?*

**A1.3:** Dedicated session on publication planning would be helpful.

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?*

**A1.4:** Perhaps split into technical and clinical streams. There was too much time spent fighting with technology when time could have been more usefully spent in other areas.

### 2. Training

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?*

**A2.1:** Venue was excellent – perhaps circulating a 'pre-requisites' paper prior to the meeting would allow partners to ensure they have the necessary software set up and configured for the meeting.

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

**A2.2:** The procedure was fine, but the software displayed fundamental issues that hampered progress. All BIRO software components must be thoroughly tested prior to wider release.

**Q2.3:** *Was the introductory description of the usage of the software appropriate?* **A2.3:** Yes

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?* **A2.4:** Work laptop.

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?* **A2.5:** Full report on issues and suggested changes were submitted after meeting

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?* **A2.6:** Both

**Q2.7:** *Were there any particular problems using the database that you can report?*

**A2.7:** Didn't get as far as using the database!

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.*

**A2.8:** Identified and documented issues with the BIRO Box and its handling of XML data not provided by co-ordinating organisation. Documented bugs and an alternative method of handling data imported from XML files.

**Q2.9:** *At the end of the session, did you succeed in:*

a) *running the BIRO software (using the BIROBox)* **A2.9a:** No.

b) *mapping data from your test dataset to the BIRO definitions* **A2.9b:** No.

c) *exporting data in BIRO XML format* **A2.9c:** Yes, this was done without using the BIRO Box.

d) *loading data on the BIRO Postgres database* **A2.9d:** No.

e) *running the statistical engine* **A2.9e:** No.

f) *producing the final BIRO report* **A2.9f:** No.

**Q2.10:** *Are you able to use the BIRO software now?*

**A2.10:** There are still issues outstanding which have not yet been resolved.

**Q2.11:** *Can you send us the BIRO report for your institution?* **A2.11:** Not available.

**Q2.12:** *Can you send us the statistical objects produced from your report?* **A2.12:** Not available.

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?*

**A2.13:** Ensure that software is fully tested, perhaps by partners who have not been involved in the development process. Objective testing and analysis cannot be completed by those so close to the system.

### 3. Training material

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? It is complete? How do you think it could be improved?*

**A3.1:** Not aware where these can be found! Can these be put on the website?

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?*

**A3.2:** The latest version checked has a lack of clarity on error display; if the application produces an error, this should be trapped and handled appropriately. Ideally, this should be a friendly message to the user and if possible a technical report of the error to be sent to the software developer for bug fixing.

Online help reachable from the GUI, for example and a quick start guide should be available. Overall the design is quite nice but there is a lack of consideration given to usability.

## EUBIROD Training Questionnaire n°13

### 1. Lectures

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?*

**A1.1:** Yes

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?*

**A1.2:** No, the topics were adequately covered

**Q1.3:** *Can you suggest any topic that was not covered?*

**A1.3:** No.

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?*

**A1.4:** No. The format that included a lot of exercises is very good and it should be maintained in the next meetings too.

### 2. Training

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?*

**A2.1:** Yes but a number of problems that need to be solved was identified.

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

**A2.2:** There were some problems with software installation and utilization. The installation process was comprehensive and time-consuming, requiring higher level of IT knowledge than can be expected from physicians.

**Q2.3:** *Was the introductory description of the usage of the software appropriate?*

**A2.3:** Yes

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?*

**A2.4:** We worked on our notebooks.

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?*

**A2.5:** Yes

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?*

**A2.6:** We worked on our institution's database.

**Q2.7:** *Were there any particular problems using the database that you can report?*

**A2.7:** There were some problems.

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.*

**A2.8:** Since the softwares required additional improvements, the process could not be carried out by participants themselves, and required engagement of IT and statistical experts. This interfered with the educational process of the workshop.

**Q2.9:** At the end of the session, did you succeed in:

a)running the BIRO software (using the BIROBox) **A2.9a: Yes**

b)mapping data from your test dataset to the BIRO definitions **A2.9b: Yes**

c)exporting data in BIRO XML format **A2.9c: Yes**

d)loading data on the BIRO Postgres database **A2.9d: Yes**

e)running the statistical engine **A2.9e: Yes**

f)producing the final BIRO report **A2.9f: Yes**

**Q2.10:** *Are you able to use the BIRO software now?*

**A2.10:** No

**Q2.11:** *Can you send us the BIRO report for your institution?*

**A2.11:** No

**Q2.12:** *Can you send us the statistical objects produced from your report?*

**A2.12:** No

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?*

**A2.13:** Softwares require additional testing before being presented at workshops.

### 3. Training material

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? it is complete? How do you think it could be improved?*

**A3.1:** The training material is good, clear enough and complete.

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?*

**A3.2:** No. The latest version that was presented to us was the version in Kuwait. After that time we didn't get any information about the new version. We also checked the restricted area on eubirod site.

## EUBIROD Training Questionnaire n°14

### 1. Lectures

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?*

**A1.1:** Although I am experienced in the approach, I found the discussions very interesting, and highly informative to trigger improvement of applications

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?*

**A1.2:** Direct Application of the BIRO Software. Case studies of diabetes registers in Europe

**Q1.3:** *Can you suggest any topic that was not covered?*

**A1.3:** Use of BIRO for research

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?*

**A1.4:** Report of Working Groups on specific issues

### 2. Training

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?*

**A2.1:** It would be better to fit all in one single large space. The problem is going step by step with unique, clear guidance. Software was partly lacking. A CD or multiple hard disks are much better than a list of software to be downloaded from the internet. A user guide was missing.

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

**A2.2:** There was no procedure and no plan of the session explained at the start. Partners did not know whom to ask and what to do in specific situations. One referent is nothing for 50 people. There is a need to coordinate the supporting team. The whole session must be controlled and planned in advance as in a theatrical representation. Everything must be taken into account. Time is an issue. Bugs must be managed and a contingency plan prepared.

**Q2.3:** *Was the introductory description of the usage of the software appropriate?*

**A2.3:** This must be divided into separate steps. Direct application is the key.

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?*

**A2.4:** I was part of the supporting team.

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?*

**A2.5:** No. However, CC must ensure BY TELEPHONE CONTACT that partners have all requirements, starting from administrative privileges. Use direct connection to people WELL IN ADVANCE.

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?*

**A2.6:** I was part of the supporting team.

**Q2.7:** *Were there any particular problems using the database that you can report?*

**A2.7:** See report from the supporting team.

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.*

**A2.8:** See report from the supporting team.

**Q2.9:** *At the end of the session, did you succeed in:*

a)running the BIRO software (using the BIROBox) **A2.9:** YES

b)mapping data from your test dataset to the BIRO definitions **A2.9:** YES

c)exporting data in BIRO XML format **A2.9:** YES

d)loading data on the BIRO Postgres database **A2.9:** YES

e)running the statistical engine **A2.9:** YES

f)producing the final BIRO report **A2.9:** YES

**Q2.10:** *Are you able to use the BIRO software now?* **A2.10:** NO

**Q2.11:** *Can you send us the BIRO report for your institution?* **A2.11:** NO

**Q2.12:** *Can you send us the statistical objects produced from your report?* **A2.12:** NO

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?* **A2.13:** See report

### 3. Training material

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? it is complete? How do you think it could be improved?*

**A3.1:** I ask for complete user and programmers guides in three formats: 5, 50 and 500 pages.

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?*

**A3.2:** The worse of all is that no one knows where to look at to download latest version. Please see report for possible improvements.

## EUBIROD Training Questionnaire n°15

### 1. Lectures

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?*

**A1.1:** The meeting was very helpful to get a view inside to the software and the data transfer. So it was more easier to speak with persons who are responsible for other data bases, to motivate them to join of our project.

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?*

**A1.2:** the working with sql database

**Q1.3:** *Can you suggest any topic that was not covered?*

**A1.3:** the export and import function

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?*

**A1.4:** working in small groups with one expert in one room with a beamer to understand more details

### 2. Training

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?*

**A2.1:** Yes for me it was OK, it good be better and time saving, if all is on one USB stick for each – last time there were problems with the version of some software programs, which we had to download from the internet

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

**A2.2:** we have lost a lot of time to install the software – It would be better, if there is a set up routine.

**Q2.3:** *Was the introductory description of the usage of the software appropriate?*

**A2.3:** Yes but to work more in a practical way in small groups is more fruitful.

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?*

**A2.4:** No it was my own laptop in Kuwait – in our hospital we are using only the computers of the clinic.

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?*

**A2.5:** see above

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?*

**A2.6:** database from the FQSD project Germany

**Q2.7:** *Were there any particular problems using the database that you can report?*

**A2.7:** no

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.*

**A2.8:** As the BIRO software was running it was not enough time to analyze the results.

**Q2.9:** *At the end of the session, did you succeed in:*

a)running the BIRO software (using the BIROBox) **A2.9a:** Yes

b)mapping data from your test dataset to the BIRO definitions **A2.9b:** Yes

c)exporting data in BIRO XML format **A2.9c:** Yes

d)loading data on the BIRO Postgres database **A2.9d:** Yes

e)running the statistical engine **A2.9e:** Yes

f)producing the final BIRO report **A2.9f:** Yes

**Q2.10:** *Are you able to use the BIRO software now?*

**A2.10:** I have not used it again – I am waiting for the new version

**Q2.11:** *Can you send us the BIRO report for your institution?*

**A2.11:** I have done it after the meeting in Kuwait

**Q2.12:** *Can you send us the statistical objects produced from your report?*

**A2.12:** I don't understand this question

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?*

**A2.13:** see above

### 3. Training material

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? it is complete? How do you think it could be improved?*

**A3.1:** which material, I have not got a new one

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?*

**A3.2:** I don't know about a new version.

## EUBIROD Training Questionnaire n°16

### 1. Lectures

**Q1.1:** *What is your opinion about BIRO Academy lectures at the First BIRO Academy Residential course? Were they interesting? Were they useful to understand the BIRO approach?*

**A1.1:** It's necessary to use a tool like BIRO academy for knowledge-transfer between participating partners. For the first lecture it has been a very widespread variety of topics. In the future it would be necessary to go more into detail concerning several topics.

**Q1.2:** *Is there any topic that you want to be covered in more detail at next meetings?*

**A1.2:** The BIRO Web Portal, which is an essential part of the BIRO system due to its promotional effect, still lacks of ideas and concepts. It should be discussed in more detail if tools for information visualisation would be more appropriate in the future.

**Q1.3:** *Can you suggest any topic that was not covered?*

**A1.3:** The concept of the BIRO system derives from the discussions of the years 2005 and 2006. Technological aspects of the system are partially antiquated. In September 2011 the Information Visualisation will be outdated. It should be discussed in more detail, which technological possibilities exist to visualise and explore data, especially for interaction with users.

**Q1.4:** *Do you suggest any change in the format of the session (broader participation, interactive panel, roundtable discussion, report of a working group)?*

**A1.4:** In the first course training sessions were arranged as a set of presentations followed by interrogations of the presenters by the audience. It would be more useful if the audience is more involved in the training lessons. This could be done through discussions of topics in smaller groups and final presentations of the results. In some cases roundtable discussions can also be useful to achieve a broader participation of the project-members.

### 2. Training

**Q2.1:** *Was the venue organized according to your needs and expectations? Were the facilities appropriate? Did you find all the necessary software installed, or available when needed?*

**A2.1:** It was not helpful for the training that project-members were split into two parts, which worked on different locations. Furthermore it was not well organized how people have to install their software. People were not able to take the whole steps for the installation. As a lesson learned JR created an installation routine for the whole BIRO-system. Hopefully the new program will encourage people to use the software and give feedback.

**Q2.2:** *Was the procedure used for training appropriate? What worked? What didn't work?*

**A2.2:** I would have appreciated if people had more enthusiasm in the training session. It was very difficult for non-informatics to get the system running. That's why people got rather uninterested in running the system. Furthermore it was not beneficial that people did not bring valid datasets to use the system. Unfortunately the sample-datasets did not work. Remaining members had little chance to produce a local report.

A success was the production of at least 5 local reports with real datasets for some countries at the end of the meeting. It was also a satisfaction for all other members to see that the system already works, but still with some major and minor problems.

**Q2.3:** *Was the introductory description of the usage of the software appropriate?*

**A2.3:** In my opinion the introduction was kind of chaotic. In combination with the fact that teams worked in different rooms it was not understandable for everyone.

**Q2.4:** *Did you work on your notebook or on a computer provided by the organization?*

**A2.4:** I worked on my notebook.

**Q2.5:** *Were there any problems with basic hardware/software installed or required to conduct training that you can report?*

**A2.5:** The system was already running on my notebook when I arrived at the meeting.

**Q2.6:** *Did you work on data provided by the Coordinating Centre as a test dataset or extracted from a local database of your institution?*

**A2.6:** I worked on data provided by our own system 'FQSD' for the year 2005.

**Q2.7:** *Were there any particular problems using the database that you can report?*

**A2.7:** No.

**Q2.8:** *Please describe at length what you have done during the training session: your experience with the BIRO software, the results achieved for each step of the session.*

**A2.8:** Due to the fact that the system worked out rather fast on my notebook, I went around and helped people to get the software installed and to get the system running on their datasets. Unfortunately I had to fix the same bugs on every partner's installation, so it was really time-consuming. My experience was that the software has not been tested before. It's absolutely necessary to use resources (personnel/money) to test and improve the software before it gets installed by the project members. We have to regard the project-members, which were not part of BIRO, as our first clients, and not as our software-testers. Otherwise people will lose their interest because we are not proceeding in our tasks for the project.

**Q2.9:** *At the end of the session, did you succeed in:*

- a) *running the BIRO software (using the BIROBox)* **A2.9a:** Yes
- b) *mapping data from your test dataset to the BIRO definitions* **A2.9b:** Yes
- c) *exporting data in BIRO XML format* **A2.9c:** Yes
- d) *loading data on the BIRO Postgres database* **A2.9d:** Yes
- e) *running the statistical engine* **A2.9e:** Yes
- f) *producing the final BIRO report* **A2.9f:** Yes

**Q2.10:** *Are you able to use the BIRO software now?*

**A2.10:** Yes

**Q2.11:** *Can you send us the BIRO report for your institution?*

**A2.11:** Yes

**Q2.12:** *Can you send us the statistical objects produced from your report?*

**A2.12:** Yes

**Q2.13:** *Any suggestions on how to improve the organization of the next training sessions?*

**A2.13:** There should be a clear roadmap what targets should be accomplished in which time. Furthermore clear responsibilities should be defined which persons are in charge of which parts. Smaller parts with defined endings and summaries should be introduced during the training sessions, so that partner's don't work without any targets for hours.

### **3. Training material**

**Q3.1:** *What do you think about the training material currently available? Is it clear enough? Is it complete? How do you think it could be improved?*

**A3.1:** Unfortunately I don't know where to download or how to get the training material for the BIRO system.

**Q3.2:** *What do you think of the BIRO software currently available? Did you check the latest version of the BIROBox GUI? How do you think it could be improved?*

**A3.2:** I designed the installer. But I don't know if there are any updates in the statistical engine, because there were some calculation errors during the meeting in Kuwait. The last version of the BIRO-Box had some bugs - hopefully they are fixed by now. An improvement could be an updater from a central server, so that project-members don't have to uninstall the old and reinstall the new version of the BIRO-Box.