EUBIROD
EUropean Best Information through Regional Outcomes in Diabetes

Executive Agency for Health and Consumers

WP2
DISSEMINATION OF THE RESULTS

DELIVERABLE D2.1

BIRO Academy Residential Course Year 1

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Dasman Center for Research and Treatment of Diabetes, Kuwait
Dutch Institute for Healthcare Improvement, Nertherlands
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Introduction

Our mission

The BIRO Academy is the major dissemination activity of the EUBIROD project. It is aimed at showing the philosophy underlying the BIRO system, the way it has been developed, the results achieved, the products delivered, and the way this approach evolves.

The Academy provides a direct opportunity to interact with a growing international network of distinguished professionals with a high level mix of expertise in the fields of health policy, clinical practice, biostatistics, epidemiology and information technology.

The BIRO Academy allows developers of diabetes registers to learn from success stories in the field of electronic medical records, participating to the further expansion of a common solution to monitor diabetes on a continuous basis by linking providers to the final users of diabetes indicators.

Through the joint support of the European Commission and the Dasman Center for Research and Treatment of Diabetes, we aim to favor the construction of a European Diabetes Register capable of spreading its benefits and collaboration well beyond the continental boundaries.

By disseminating the BIRO approach among partners of the EUBIROD Consortium, the Academy paves the way for further organizations to join a global platform for the open exchange of knowledge and software.

For this purpose, the BIRO Academy welcomes all third parties interested in "building a common European infrastructure for standardized information exchange in diabetes care, for the purpose of monitoring, updating and disseminating evidence on the application and clinical effectiveness of best practice guidelines"

Our strategy

In the framework of the EUBIROD project, the BIRO Academy provides a series of three Annual Residential Courses hosted by the Dasman Center for Research and Treatment of Diabetes in Kuwait City, Kuwait. Courses are structured in lectures and practical sessions, where participants get acquainted with the usage of diabetes data and application of the BIRO system.

The Academy website will make available all materials produced during the Annual Residential Courses by means of multimedia, including slides, videos, demo applications, software and other training materials.

The BIRO Academy includes also an e-learning platform that contains self-administered tests and questionnaires to evaluate the effectiveness of the training activity.

Sponsorship

The EUBIROD Project is co-financed by the European Commission, DG Health and Consumer Protection through the EACH Agency (Executive Agency for Health and Consumer Protection).
Annual Residential Courses are fully supported by the Dasman Center for Research and Treatment of Diabetes, under the auspices of the Kuwait Foundation for the Advancement of Sciences.

Materials

•First BIRO Academy Residential Course (Kuwait City, 2nd-4th May 2009)

•Second BIRO Academy Residential Course (Kuwait City, 2010)

•Third BIRO Academy Residential Course (Kuwait City, 2011)

Aim and achievements of the First Residential Course

The First Residential Course includes material from the 1st Annual EUBIROD meeting held at the Dasman Center for Research and Treatment of Diabetes in Kuwait City, Kuwait, 2nd-4th May 2009.

The main aim of the Course, as part of the activity of the BIRO Academy, is to induct partners of the EUBIROD Consortium to the approach developed in the project "Best Information through Regional Outcomes" (BIRO) and to disseminate the scope, materials and results delivered to a wider international audience through the complete coverage of the session available online.

The secondary aim of the Course is to provide the basis for EUBIROD partners to apply these concepts by using the BIRO software either on test data supplied directly by the Faculty, or on real datasets extracted by themselves from local registers.

The Course includes a series of lectures from a selected international panel of thirteen experts, the "BIRO Faculty" (Table 1), involved in the development of the BIRO system and using diabetes information for policy making on a routine basis.

Lectures at the First Residential Course are organized around four themes (Table 2): 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 for the audience to interact with the Faculty and stimulate provocative comments, as witnessed by the abstracts and video coverage.

Over 50 participants from 20 countries attended the meeting (Table 3).

The contents of the session are made fully available as abstract, flash movie, and slides, at the EUBIROD website (www.eubirod.eu), through a link to the "BIRO Academy", currently only accessible from the restricted area for 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. This will allow us to grow a "BIRO Community" of certified stakeholders that can support the expansion of the action.

The enlargement of the BIRO community will provide the opportunity to include more experts in the Faculty, thus making the organization of future Courses an exciting and dynamic event, in line with the evolution of diabetes information and the further refinement of the BIRO system.

The Second Residential Course is expected to take place in the same period of the year 2010 in Kuwait City. An e-learning platform based upon all subjects taught by the Academy will be added to the BIRO Academy section in late 2010 as an optional training activity for all Alumni. The contents of the First Residential Course constitute Deliverable D2.1 of the EUBIROD Project: "BIRO Academy Residential Course Year 1", an activity of WP2: "Dissemination of the Results".

Proceedings and materials of the training session held at the 1st Annual EUBIROD meeting are part of Deliverable D4.1 of the EUBIROD Project: "Training Session", an activity of WP4: "Training".

Table 1. The BIRO Faculty at the First Residential Course

Azzopardi Joseph, University of Malta, Malta
Baglioni Valentina, University of Perugia, Perugia, Italy
Beck Peter, Joanneum Research, Graz, Austria
Bennakhi Abdullah, Dasman Center for Research and Treatment of Diabetes, Kuwait
Carinci Fabrizio, Serectrix, Pescara, Italy
Cunningham Scott, University of Dundee, Dundee, Scotland
Di Iorio Concetta Tania, Serectrix, Pescara, Italy
Massi Benedetti Massimo, University of Perugia, Perugia, Italy
McAlpine Ritchie, University of Dundee, Dundee, Scotland
Pruna Simion, Institute Paulescu, Bucharest, Romania
Samuelsen Kristian, NOKLUS, Bergen, Norway
Storms Fred, Dutch Institute for Healthcare Improvement, Utrecht, Nertherlands
Traynor Vivie, Ministry of Health, Cyprus

Table 2. Contents of the First Residential Course

Best Information through Regional Outcomes
Building a shared diabetes information system for policy and practice

Theme 1. Background, Objectives and Data

- The BIRO Project *(F. Carinci, U.Perugia, Italy)*
- Evidence-base for EU diabetes information *(F.Storms, CBO, Netherlands)*
- Standardized Diabetes Data Definitions *(S. Cunningham, U.Dundee, Scotland, UK)*
- Discussion

Theme 2. The BIRO System

- Standardized European Diabetes Reports *(F.Carinci on behalf of S.Skeie, NOKLUS, Norway)*
- Privacy Impact Assessment *(C.T. Di Iorio, Serectrix, Italy)*
- The BIRO System Infrastructure *(V. Baglioni, U.Perugia, Italy)*
- Distributed Statistical Analysis Software *(F.Carinci, Serectrix, Italy)*
- The BIRO Web Portal *(K. Samuelsen, NOKLUS, Norway)*
- Discussion

Theme 3. Implementation and Usage

- Technology Transfer in Romania *(S.Pruna, Paulescu Institute, Romania)*
- Technology Transfer in Cyprus *(V.Traynor, Ministry of Health, Cyprus)*
- Security, Integration and Implementation *(P.Beck, Joanneum Research, Austria)*
- BIRO Software *(V.Baglioni, U.Perugia, Italy)*
- Discussion

Theme 4. Regional Diabetes Registries for policy and practice

- The relevance of diabetes policy in Kuwait, Yousuf Al Naifs *(Undersecretary of State, Ministry of Health, Kuwait)*
- Address of the EU Presidency, Martin Vàvra *(Ambassador of the Czech Republic in Kuwait)*
- International collaboration for health policy, Enrico Granara *(Ambassador of Italy in Kuwait)*

- Diabetes in the Gulf Area *(A. Ben-Nakhi, Dasman Center, Kuwait)*
- The EUBIROD project *(F. Carinci, Serectrix, Italy)*
- The Tayside Diabetes Register *(R.Mc Alpine, U.Dundee, Scotland, UK)*
- Diabetes Registry in Kuwait *(M. Massi Benedetti, Dasman Center, Kuwait)*

Table 3. Participants to the First Residential Course

Guest Authorities
Al Naifs Yousuf, Ministry of Health, Kuwait
Arouj Monira, Dasman Center for Research and Treatment of Diabetes, Kuwait City, Kuwait
Ferbuyt Michael, Dasman Center for Research and Treatment of Diabetes, Kuwait City, Kuwait
Granara Enrico, Embassy of Italian Republic, Kuwait
Vàvra Martin, Embassy of Czech Republic, Kuwait

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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, Kuwait
Battelino Tadej, University Children's Hospital, Ljubljana, Slovenia
Bazzoffia Marco, University of Perugia, Perugia, Italy
Boran Gerard, The Adelaide and Meath Hospital Dublin, Ireland
Bratina Nataša Uršič, University Children's Hospital, Ljubljana, Slovenia
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
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Scerri Simon, University of Malta, Malta
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ABSTRACTS
OF COURSE LECTURES

Theme 1.

Background, Objectives and Data

Theme 1. Background, Objectives and Data

The BIRO Project *(F. Carinci, U.Perugia, Italy)*

The project "Best Information through Regional Outcomes" (BIRO) bears upon a systematic, evidence-based approach to improve management and prevention of diabetes complications in Europe through better information at all levels. The EU proposal envisaged a new model for international benchmarking of quality and outcomes through a shared system capable of delivering diabetes indicators in a sustainable and automated fashion. In this presentation **Dr.Fabrizio Carinci**, a senior biostatistician and Technical Coordinator of the project for the University of Perugia, presents the main features in the design and development of the BIRO project. Fabrizio introduces its general objectives and explains how the plan for BIRO aimed at overcoming a number of unresolved issues that are practically relevant, for which the availability of better information is key to act. The BIRO proposal came at a time when both the IDF and the EU Council recommended continuous monitoring and benchmarking as top priority for diabetes in Europe.

Bearing upon his background and diverse expertise on field at international level, Fabrizio provides an overview of the many technological advancements at the basis of an integrated solution. He explains how the BIRO design was inspired by strategies that were perceived to be crucial, including: using different sources of information; involving databases already in place at the regional level; defining an architecture that could ensure privacy and confidentiality according to international standards; using open source software to allow the widest dissemination of the software and modern technology for online reporting.

Dr.Carinci highlights the importance of a particular notion: the "region" intended not as an administrative entity, but as a network of centres sharing a homogeneous set of organizational aspects, including the definition of individual data items and the way parameters are measured and routinely collected. This way the concept of region (and the annexed information system infrastructure) can be flexibly applicable to any relevant level, from a diabetes clinic to a collaborating network, or even an entire country. To allow compatibility with the BIRO approach, a data dictionary would allow collaborating "regions" to map their own definitions to those adopted by the BIRO network.

Dr.Carinci presents the BIRO workplan, its 15 workpackages, and the main results obtained in 40 months between 2005-2009. He describes the clinical review, leading to the specification of parameters and indicators, the common dataset and data dictionary, fully developed in XML, the template adopted for BIRO reports. The agreed architecture was identified through a privacy impact assessment allowing specification of details for data transmission, and driving all software development, including: database tools written in Java and Postgres, the statistical engine based on R and Latex, communication software using web services, and the web portal realized in Drupal. The system was completed by developing an integrated GUI interface automating the usage of all functions. The BIRO system runs on both Linux and Microsoft systems, and is released as open source under the GPL.

Dr.Carinci concludes his presentation explaining how the BIRO system is now being rolled out to a network of clinical units, regions, and Member States, as a basis for the creation of a European Diabetes Register, towards which the EUBIROD project will continue to disseminate, apply and refine the BIRO approach.

Theme 1. Background, Objectives and Data

Evidence-base for EU diabetes information *(F.Storms, CBO, Netherlands)*

The BIRO project proposes the creation of a Shared "Evidence-Based" Diabetes Information System to support European health policy. The essential items to be collected must be continuously revised, taking into account the actual relevance of new knowledge on diabetes for population health and everyday practice.
In this presentation, **Dr. Fred Storms**, a clinical diabetologist from CBO, Netherlands, presents the aim and contents of the clinical review conducted by Joanneum Research for the BIRO Consortium. Fred introduces the main results and how they have been summarized into indicators that were used to propose a set of relevant measures to be collected routinely for benchmarking of diabetes prevention and care across Europe.
In a first step existing guidelines were viewed. Comments, literature references and potentially interesting data items were extracted and clustered per thematic area. Fred explains how a data item per definition is considered as being "one single piece of data" or "the smallest piece of information that can be obtained from a survey or census". Several new or modified items were suggested by the review. In a second step indicators were defined, whereby indicators are seen as "a measure used to determine, over time, performance of functions, processes, and outcomes". The selection of indicators was carried out along the recommendations for indicator evaluation developed by the US Institutes of Medicine and applied by the OECD Quality Indicators Project. According to this approach, indicators have to be relevant, secondly, they have to be scientifically sound, and thirdly, they have to be potentially feasible. In a third step the indicators were rated according to the above mentioned scheme in a consensus process within the consortium.
Dr. Storms, as a former coordinator of the EUCID project, explains how he is interested in the feasibility component, as it frequently happens that such indicators are hard to collect, particularly at national level. As a matter of fact, out of N=85 candidate indicators initially suggested, only N=49 were finally selected as being relevant for BIRO. The level of feasibility was taken into account when defining the data items required for computing such indicators. As a result of the clinical review, a key list of BIRO indicators were selected, then divided for convenience into specific chapters: epidemiology, structural quality, process quality, intermediate outcomes and terminal outcomes. More details on these indicators are included in the report template section of the project.
Fred concludes his presentation by remarking that the set of indicators herein described as candidate for inclusion in the BIRO system needs to be carefully assessed after a "BIRO core data set" is implemented in real life conditions, to be duly maintained by all participating regions and eventually democratically expanded.
One of the problems remains the necessary continuous update of this revision, which is natural due to the constant evolution of care processes and the data itself along time.

Theme 1. Background, Objectives and Data

Standardized Diabetes Data Definitions *(S. Cunningham, U.Dundee, Scotland, UK)*

Core diabetes indicators for the BIRO project were identified in a clinical review of current evidence. In order to allow accurate comparisons of diabetes indicators, a standardised currency for data storage and aggregation is required.
Objectives of standardized diabetes data definitons were to define the BIRO Common Dataset and to explain 'data about the data' through a data dictionary and annexed series of XML documentation that would be widely available to authenticate the contributing information.
In his speech, **Scott Cunningham**, a technical consultant from the University of Dundee, Scotland, UK, reports his direct experience in the BIRO project as leader of the Common Dataset and Data Dictionary workpackages. He reports how an initial review of the clinical datasets used by all partner institutions was seen as fundamental to understand the level of consistency in terms of recording, data definition and units of measurement across participating centers. Based upon these characteristics, high priority items were selected, and, where necessary, data mappings and algorithms were specified in order to allow partners to meet the standard definitions. Data was then assigned a "validity" weight (high, medium or low) describing how well it could meet the agreed definitions. Based on such key requirements, a series of descriptive elements were created to document the 'metadata' for each of the records gathered. The first set of metadata describe the standardised elements, documenting units of measurement, data type, range values, definition, validity, mapping criteria etc. The second set of metadata must be provided by each partner in order to document how consistent their local systems are with the standard definition. Information gathered at this stage includes consistency with definition, completeness of local data and an overall quality score.
In the presentation, Scott describes the common dataset, including N=82 data items, of which N=53 describe clinical data e.g. clinical and process outcomes, N=21 were created to specify information regarding the local clinical site and N=8 to include geographical references. The classification allowed to gain a detailed understanding of clinical processes and local geography. These mappings and standardised definitions have been used to create an electronic directory for diabetes care, providing the foundation for the BIRO data repository. Clinical and non-clinical information has been gathered using a standardised XML data structure containing supplementary comments required to fully document the data analyses.
Scott Cunningham highlights how the development of data dictionaries and data standards can be used to improve the quality, relevance, consistency and comparability of national information about health. In BIRO, a European minimum common dataset and data dictionary have been developed to allow wide applicability in diabetes registers. The process will continue as the project expands for the EUBIROD project.

Theme 1. Background, Objectives and Data

Discussion

The discussion has been opened by **Prof.Massi Benedetti**, addressing the issue of the continues evolution of the clinical review and list of parameters, thresholds and indicators, which in turn may pose the question on how to compare results obtained using different classification systems. Also, there is a need for the coexistence of different indicators, as in the case of BMI, which must be differently applied to different populations. The case applies not only to international comparisons, but also within EU countries, as these are becoming increasingly multi-ethnic. According to **Fred Storms**, in the BIRO classification there should be more attention on risk categories than "normal", which usually involves 95% of the population. Furthermore, ethnicity must be measured more routinely and be included in the common dataset. That is increasingly acknowledged by healthcare organizations, since it is understood that the characteristic is important to treat subjects properly. Another example is Hba1c, whose optimal level is still under debate, but must be indeed discussed because studies show that attention to lower it actually improves outcomes.
According to **Prof.Zeliko Metelko**, Professor of Internal Medicine at the School of Medicine, University of Zagreb, and Director of the Vuk Vrhovac University Clinic for Diabetes, one should look at actual data definitions and choose best indicators from different angles. One example is the index albumin/creatinine, which can be a better descriptor than microalbuminuria per se. The same applies to Hba1c, for which a lower level of 6.5 can be acceptable as a cut off considering the evidence from the UKPDS. According to Prof.Matelko, the combined BIRO report should be definitely flexible and perhaps allocate more levels. However, we need also to take into account indicators for primary care prevention, e.g. education or weight gain as a percentage deviation from an optimal level. In response to Zeliko, **Scott Cunningham** remarks that the dataset can be revised and more items can be added at any time with the evolution of the BIRO system and the registers. **Fred Storms** states that the BIRO Consortium has taken into account that some of the parameters are not standardized, including the ration of albumin to creatinine.
In response to a question from the audience, **Scott Cunningham** reports that in Scotland the entire diabetic population is covered by the electronic register.
According to **Fabrizio Carinci**, the scope of registers, and then that of BIRO, is to use information in real practice conditions to improve patients' outcomes. The whole registry is for quality, thus the same applies to the choice of levels, which should be given the highest priority in consideration of the direct interest of patients. In this regards, the case of Cyprus in BIRO represents a real success story since local managers used definitions to actually start a new registry.

Theme 2.

The BIRO System

Theme 2. The BIRO System

Standardized European Diabetes Reports *(F.Carinci on behalf of S.Skeie, NOKLUS, Norway)*

A central element of the BIRO project is the ability to report diabetes outcome indicators for different regions in Europe. The creation of standardized reports requires the identification of a precise design for the output that can be usefully replicated. A template constitutes the basic reference which, through an agreed preset format, can be used repeatedly each time the report is applied or subsequently adapted.

In this presentation, **Dr.Fabrizio Carinci**, on behalf of Dr.Svein Skeie, clinical diabetologist from NOKLUS, Norway, explains how partners have collaborated to define a reports template from the initial set of indicators defined by the clinical review. The template defines specifically how BIRO results are to be displayed and explained on the web portal, taking into account the needs of different types of audiences, which reflect the different areas covered by the project: governance, health care, research and people with/without diabetes.

To realize the template, all data items and indicators from the clinical review have been listed in a table and assigned a specific level of priority and feasibility, where priority relates to the level of importance of its inclusion in the report, while feasibility indicates the possibility that the indicator could be practically estimated. Only data items and indicators with high priority and high feasibility were included in the final reports template. For each data item and indicator, any strata for output have been also indicated. A revision of graphical displays for diabetes reporting released by major agencies worldwide has been also undertaken. Best options have been selected as target statistical outputs for each category of audience, by data item and indicator, as well as the HTML code that would practically deliver results obtained by the application of the statistical engine.

Finally, a total of 72 data items/indicators were chosen, with an indication of the target audience and description of target statistical outputs. Results obtained have been directly submitted to the designers of the statistical engine and developers of the web portal to produce and organize all BIRO outputs accordingly.

Dr.Carinci, as a statistician involved with Norvegian partners to define the structure of the report, reminds that for statistical reports to be best informative, they must strictly relate to the evidence base. The range of indicators must be restricted to those most reliable, computed properly using standardized methods. Fabrizio concludes by remarking that through an objective procedure, the BIRO system has identified a minimal template that corresponds to the agreed set of indicators, referenced by a basic set of graphical outputs chosen among those currently available in diabetes reports worldwide.

Theme 2. The BIRO System

Privacy Impact Assessment *(C.T. Di Iorio, Serectrix, Italy)*

The BIRO Information System involves the use of sensitive-medical data collected through diabetes registries within national boundaries and further processed for public health studies at the international level. Privacy impact assessment is a systematic and flexible process for evaluating a proposal/project in terms of its impact upon privacy, which has been specifically adapted to the BIRO context. In this presentation **Dr. Concetta Tania Di Iorio**, a legal expert leader of the privacy impact assessment for Serectrix, explains how the process allowed to provide a description of relevant privacy risks, legislation and mitigation strategies, and the methodology that led to the successful identification of the best architecture for the BIRO Information System. In her talk, Tania describes the various steps involved in the conduction of the assessment. A multidisciplinary team carried out a preliminary systematic review of the privacy literature, followed by a general discussion on the data flow. Data flow analysis focused on alternatives identified in the first step. A Delphi consensus procedure defined the best alternative through the production of data flow tables (possible scenarios for the collection, use and disclosure of personal information/data, with related options) information flow questionnaire (marks for each scenario/option); overall consensus table (ranking all alternative architectures, scenarios and options). Privacy analysis covered issues arising in data transfer from local centres to the central database. Potential privacy risks have been identified and thoroughly analysed through a summary table indicating mitigation strategies to be implemented. The level of risk was classified according to an ordinal scale of intensity.
Dr. Di Iorio reports that three main candidate architectures were initially identified: "individual patient data, de-identified through a pseudonym"; "aggregation by group of patients, with Centre's identifiers available in de-identified form, securely encrypted"; and "Aggregation by Region". Data flow analysis selected the second as the best solution in terms of privacy protection, information content, scientific soundness and feasibility. Following this step, privacy analysis performed a detailed assessment of the various aspects involved in the adoption of the final BIRO architecture. The transfer of information occurring in the system, based upon the exchange of de-identified data and targeted mitigation strategies, corresponds to a low level of privacy risk. Tania explains how according to the EU Data Protection Directive, BIRO can be placed outside the scope of the data protection principles therein contained. The system processes only statistical objects stored as aggregate comma delimited files: there is no possibility, according to the state of the art, to identify a patient, either directly or indirectly, with a reasonable effort. Aggregate data processed by the local database engine are sent to the central statistical engine through "ad hoc" communication software ensuring secure information exchange and compliance with security requirements enshrined in EU and international data protection norms. Therefore, further processing by the global statistical engine cannot pose any privacy risk, either directly or indirectly. Trans-border data flow envisaged in BIRO is legally viable according to the EU legislation. Publication of project results is performed to avoid any direct/indirect identification of data subjects and/or local centres. In conclusion, privacy impact assessment shows that the selected BIRO architecture fulfils privacy protection requirements by addressing and resolving broad privacy concerns from different angles.

Theme 2. The BIRO System

The BIRO System Infrastructure *(V. Baglioni, U.Perugia, Italy)*

The BIRO approach is based on the strategic development of a specialised system that involves standardized processing of electronic medical records and routine data exchange across collaborating centres. The local application of the system provides the method for each centre to extract relevant data from local data sources, performing the same standard statistical analysis and producing a comparable report for selected BIRO indicators. Further to that, there is a need to safely send aggregated data towards a central server that would compile and process all aggregate data to derive an overall statistical report.

In this presentation, **Eng.Valentina Baglioni**, software engineer and project manager of the BIRO project for the University of Perugia, provides an overview of how the Consortium has developed the BIRO framework and integrated all the different components for the implementation of its general architecture.

Here Valentina shows a series of technical slides starting from the description of the entire process, and providing insights into the local BIRO system that has been specifically developed to manage the core tasks foreseen by the BIRO architecture.

The local BIRO system establishes a connection with the local database where clinical data are stored, extracting relevant records according to specifications given by the common dataset through the "BIRO Adaptor", resulting in XML BIRO export files.

Data concerning a single patient, the profile and the clinical episodes clustered by episode date are then loaded into a BIRO local database using the "BIRO Database Manager". The system triggers execution of the BIRO statistical engine to produce the local report and partial results files that are sent to the central BIRO system via Communication software. By compiling results from different centres, the central server produces results for the whole population starting from partial results coming from multiple sites. A central component of the statistical engine deploys the overall BIRO statistical report. In an attempt to transfer BIRO technology easily and effectively, a graphical user interface, the "BIROBox", has been developed to provide users with a simple instrument capable of managing all functions and the different steps required for the application of the local BIRO system.

Furthermore, Eng.Baglioni briefs about the results obtained in accordance with directions provided by the Privacy Impact Assessment, so that international results for diabetes indicators are obtained without transferring sensitive data out of the boundaries of the local system. Most importantly, the use of the local BIRO System does not require any changes in the way data are gathered, but it offers additional tools that any centre can routinely use to compare own practice against other units.

Theme 2. The BIRO System

Distributed Statistical Analysis Software *(F.Carinci, Serectrix, Italy)*

Sustainable solutions for the routine provision of strategic data across Europe require highly collaborative frameworks. The BIRO approach is based on a collectively agreed application of two consecutive data processing steps, locally and centrally, each one involving key statistical procedures. A "Statistical Engine" is specifically required to derive aggregate tables from databases held at the regional level that will be sent towards a central BIRO server.

In this presentation, **Fabrizio Carinci**, a senior biostatistician leading the development of the statistical engine for Serectrix, describes how specialised software has been built to run the same routines in each partner's region, by exporting local data to a standardized database, formatted according to common criteria, that is further processed by R software.

Fabrizio explains how the method can be used to implement and disseminate the use of advanced statistical methods for the production of diabetes indicators and the analysis of population-based data. Open source statistical software is today extremely powerful and may allow users replicating and further extending the approach for their own purposes.

The R software has been adopted as a development platform for all BIRO statistical software. A statistical engine connects to the local database using R Postgres drivers. Through the notion of "statistical object", tables are created to store aggregates of local data (e.g. the arithmetic mean, percentile, variance, etc.) as flat text comma delimited files. A taxonomy defines all objects being implemented. The BIRO report template has been used as a guide for data processing and consequent transfer to the central server, where the central statistical component runs the overall analysis for the delivery of the global report.

Dr.Carinci explains how the BIRO statistical and central engines have been successfully developed to work on different platforms, being tested on both Vista and Linux. In terms of performance, average hardware allowed completing a full local BIRO report from a test sample of more than 5,000 patients and several thousands episodes in about 7 minutes. The central engine, using aggregate data from N=5 centres, corresponding to over 43,000 subjects and 273,000 episodes, completed the entire process of statistical analysis and production of a full overall report in 22 minutes. Installation of the software is identical regardless of the hardware, requiring R>1.8, Latex, Java 6.0 and PostgreSQL, plus various additional libraries/packages included in the distribution packages. All R functions are released under the GPL license and made available to partners of the Consortium bundled with all other BIRO components.

In his conclusions, Fabrizio highlights that the statistical engine provides a platform for accurate benchmarking that currently does not exist in its innovative form at the point of health care provision. The system may serve multiple users, from the European Union, to the local physician. Users, once inducted to using the software, can apply it independently and submit better aggregate data to the central server, safeguarding sensitive data as a result of the application of rigorous rules set by the BIRO privacy impact assessment. The free availability of a modern statistical component can help disseminating the BIRO approach across Europe.

Theme 2. The BIRO System

The BIRO Web Portal *(K. Samuelsen, NOKLUS, Norway)*

A single point of access to the main products developed by the BIRO Consortium allows to connect developers to data contributors and users of the system. Providing quick links to the most essential aspects of quality of care and health status in diabetes can make a change by highlighting levers of improved policy through a user friendly interface. A specific, well designed mechanism may allow to directly browse outputs of selected indicators produced by the statistical engine, directly embedded in a highly customizable presentation style.

In this presentation, **Kristian Samuelsen**, a software programmer for NOKLUS, introduces the main technical aspects involved in the construction of the web portal that will allow users of the shared information system to navigate through the materials, methods and results obtained by the BIRO system.

The portal was developed using established open source standards e.g. the Apache webserver, Postgresql database, PHP, XML and Eclipse PHP. Drupal software has been extensively used as an open source content management framework, allowing to control content-management, security, database-connectivity and menu-system, through which web administrators can maintain and update the portal with minimal requirements for source coding. Collaborative work among members of the BIRO Consortium allowed to define a common design for the web portal, and produce its content according to own skills and expected contribution.

Kristian shows how the functionality provided by the web portal allowed solving two different complexities: (i) providing facilities and utilities for handling the texts and documents displayed, the layouts of pages, navigation menus and links; (ii) organizing indicators and other reports in a way that could be regularly updated through a particular programming mechanism.

Using Drupal, indicators are refreshed automatically, consistently with the reports template, without requiring the storage of separate pages on the portal web site. Each indicator is included into a block of an XML structure defining how the items displayed, (charts, tables, texts etc.), and their layout are specified, allowing direct use by the web application to configure the display. In addition, for each indicator a small HTML block has also been written, defining the form of the output that is directly deployed by the statistical engine providing the corresponding estimates for the requested report.

Kristian concludes by remarking that the structure, mechanisms and 'open source' nature makes the portal an easily adaptable starting point, through which the Consortium can grow a more complete interface for the continuation of the program.

Theme 2. The BIRO System

Discussion

Dr.Fred Storms open the discussion by stating that the flow or information in BIRO may be considered bidirectional: the system collects data, but can also receive questions, to allow users to interact with the central engine. According to **Dr.Concetta Tania Di Iorio**, this development is possible but may cast questions on security and data protection, albeit data travel in aggregated form. However, the level of security ensured by BIRO is high enough to plan this feature. For **Fabrizio Carinci**, the option can be developed in EUBIROD. Some partners asked for customized benchmarking, but that must be discussed to understand whether it is proper for the scope of BIRO.
Prof.Joseph Azzopardi asks whether BIRO complied with local legislation in all countries, to make sure that the system can be actually operated by all partners: the EU Directive may pose specific problems in different countries. **Tania** answers that a questionnaire was submitted to all partners to better understand the situation locally. However, in the BIRO process, as a result of the privacy impact assessment, the transfer of aggregate data should not impede international data exchange. Nevertheless, the situation must be better explored in the framework of EUBIROD, with more attention to the management of registers on a per case basis.
As far as the technology is concerned, **Eng.Valentina Baglioni** remarks that the BIRO structure may be replicated in other countries in a recursive fashion. All software may be adapted to the particular needs at a national level. That means that the central engine can be installed at a national coordinating centre, linking regions that use the local engine to produce reports and send aggregate data for national indicators.
Dr. Carine de Beaufort, specialist in pediatric diabetes from Luxembourg, asks about the relationship between the BIRO server and EUROSTAT. According to **Fabrizio**, this topic must be discussed with SANCO and EAHC, since there are many overlapping initiatives and it does not seem so simple to work with the EU statistical system on a routine basis in a BIRO fashion. The whole issue is about sustainability, i.e. whether it is possible to establish a continuous flow between institutions and projects. Some innovative approaches supported by the EC e.g. EUPHIX exist but have an unclear future. By the way, the BIRO Consortium would be keen to discuss options in Brussels.
Dr.Christian Awaraji, a researcher from Dasman, warns the Consortium that the confusion between anonymization and aggregate data must be avoided, and that it should be clear that only aggregate tables are sent to the server.
Dr.Michael Jecht, diabetologist from Havelhöhe, Berlin, remarks that if BIRO will be used to publish results on local data in local journals, rather than only been sent to a central server, then it would be perceived very positively as a useful tool for clinicians. According to **Fabrizio**, due to the innovative design of BIRO, this situation is entirely possible. The software can be used for own purposes, so with some additional resources language can be changed, application can be adapted, and local needs become a direct target of BIRO.
In relation to the data server and web portal, **Dr.Christian Awaraji** asks who will responsible for data transfer to the server. **Fabrizio** informs that it needs to be clarified. For **Storms**, the central server should be in Perugia and allow benchmarking

across countries/regions. For **Fabrizio**, the development of EUBIROD may include that option, since it can boost the collaboration for many different reasons. For **Samuelsen**, the actual organization of the web portal is a topic that needs to be discussed with great attention.

Theme 3.

Implementation and Usage

Theme 3. Implementation and Usage

Technology Transfer in Romania *(S.Pruna, Paulescu Institute, Romania)*

In Romania, several experiences were made along the years in the field of diabetes information systems. In this presentation **Dr.Simion Pruna**, a senior scientist in information technology from Paulescu, presents the main results of the technology transfer.
In his talk, Simion congratulates with the team of the BIRO project, described as one of the most innovative groups since the early nineties, when similar programs have been launched, but the technology, in particular open source software, was much less developed.
Simion has been working for many years to similar initiatives, starting from a Diabcare database in Bucharest and 10 other counties of Romania. The St Vincent Diabcare data collection service was initially organized through an e-mail network linking university teaching with diabetes care centres through the same interface.
The aim of the technology transfer in BIRO is to test in real practice conditions what initially designed purely on a theoretical ground. Here Simion remarks that there is substantial work required to implement a system e.g. BIRO. The first hurdle is the retrieval of original data that must be mapped against a common format as a basis for the production of 72 diabetes indicators. To populate this matrix can be harder than previous experiences e.g. Diabcare, already described to be heavy by distinguished researchers.
In his talk, Dr.Pruna described how technology transfer allowed partners to focus on healthcare systems, the IT infrastructure, and database collection programs in three New Member States: Cyprus, Malta and Romania. This experience showed that some basic aspects in data management are indeed relevant to succeed in promoting a shared information system. For instance, data types used in different databases can be heterogeneous and need to be compared to the common format. In BIRO we found that parameters are measured and recorded differently across partners.
That is not surprising in Romania, where the same problem exists within the country and the framework appears very fragmented and not allowing interoperable services. The result until now has been poor use of health data. Health information systems in diabetes are fragmented, inaccurate, cumbersome, untimely, and isolated. Furthermore, there are implicit business incentives for limiting the interoperability of different health information systems, leading to a diversity of attitudes and mix of skills that must be faced in the implementation of new protocols.
According to Simion, today we have powerful open source solutions that can dramatically help overcoming these problems, e.g. PostgreSQL, allowing to apply highly performing queries on data using average hardware on Linux OS. BIRO complies with this framework and allows to operate in difficult conditions where the infrastructure is limited.
In his conclusions, Simion highlights that now regions can deliver useful outputs. However, to make the process easier, the technology transfer exercise must be continued with the support of customized tools that are user oriented. Tests on Romanian data show that using BIRO is not only possible, but easily transferable. To succeed, it will be paramount that clinicians, scientific associations, and policy makers are all involved in this process of innovation.

Theme 3. Implementation and Usage

Technology Transfer in Cyprus *(V.Traynor, Ministry of Health, Cyprus)*

The aim of technology transfer in the dissemination of a diabetes information system is to ensure that the same approach is relevant and applicable to different situations across Europe. The BIRO project explored difficulties in the use of medical records and obstacles, risks and incentives to the adoption of a shared information system for diabetes through a targeted activity.

In her speech, **Vivie Traynor**, a specialist diabetes nurse, presents the Cyprus experience as part of the BIRO technology transfer evaluation.

Vivie explains how important it was to share and discuss the implementation of a diabetes register in practice through direct contact with international experts in the field. As a specialized nurse, she describes her experience as being extremely useful to the process of care provision. In the program, she has visited diabetes clinics and learned specific aspects of disease management related to the collection and use of medical records on a routine basis. That is what she describes as one of the hidden, unwritten assets and benefits of the BIRO program.

In her presentation, Vivie summarizes the case of Cyprus as a demonstration of how a EU health information project may deliver practical results for health policy improvement.

The diabetes program was originally made several years ago in the collaboration with the WHO. However, the plan never took off until the startup of the BIRO project in 2005. Through the enthusiastic participation of colleagues from the Cyprus Ministry of Health, plans for diabetes data collection were discussed and finalized, and the first diabetes clinic in Larnaca was created, beginning operations for the implementation of the Diabetes Register. The electronic database software entered into action in April 2007 as a product of the Department of Information Technology Services. An Access database was made available to collect all data items included in the BIRO common dataset, with some further customizations and refinements. The database was installed at the Larnaca clinic, where all existing data recorded up to the present, plus three rural health centres are routinely recorded in electronic form. All rules relating to data protection are adhered to and every person that is on the register has signed a consent form.

Vivie reports that the expansion of the care program in diabetes and the adoption of the BIRO data collection program across the island is now agreed and will take place in stages according to a five year plan. As a result, the three rural health centres in the Larnaca and Famagusta areas which have been collaborating with the Larnaca clinic have now got diabetes specialist nurses working part time, contributing vastly both at care and education of people with diabetes, and also in data collection. The Paphos General Hospital on the west of the island has also started to collect data for the program.

Vivie concludes highlighting that she is glad to continue the international collaboration through the EUBIROD project, as part of a strategy that at the same time contributes to the European Union as well as improves both the regional and national strategy in Cyprus.

Theme 3. Implementation and Usage

Security, Integration and Implementation *(P.Beck, Joanneum Research, Austria)*

The BIRO system includes routines to send aggregate tables towards an automated server, pooling results from all sites and delivering the European Diabetes Report. Such routines must be part of a secure environment that is in charge of safeguarding the BIRO network.
In this presentation, **Eng. Peter Beck**, a senior software engineer from Joanneum Research, describes the information flow used for secure communication in BIRO.
The Consortium has regarded web services as the most suitable approach for communications. Several protocols/standards have been selected for the scope. SOAP, a lightweight protocol intended for exchanging structured information in a decentralized, distributed environment, has been adopted for its use of XML technologies to define an extensible messaging framework, providing a message construct that can be exchanged over a variety of underlying protocols.
Peter describes how the BIRO framework has been designed to be independent of any particular programming model and other implementation specific semantics. The web service allows to support interoperable machine-to-machine interaction over a network. It provides a standard means of interoperating between different software applications, running on a variety of platforms and frameworks.
In particular, Peter Beck explains why Apache Axis2 was considered as the most suitable and reliable product: it is a core engine for creating web services and transmitting SOAP messages according to the implementation of the W3C's SOAP submission, and a fully consistent open-source framework written in Java and licensed under the Apache Software License.
In terms of security, BIRO adopts Apache Rampart for its possibility to integrate OASIS' WSS-specification in Apache Axis2. From the point of view of Service Provider and Service Requester, the communication software adopts the Public Key Infrastructure as a term used for a framework that enables secure exchange of information based on public key cryptography. By this means, the system allows identities (of people, organizations, etc.) to be bound to digital certificates and provides a means of verifying the authenticity of certificates. It encompasses keys, certificates, public key encryption, and trusted Certification Authorities who generate and digitally sign certificates.
The above solutions have been implemented in the form of Java libraries that are distributed and fully integrated with the current release of the BIRO software.
In the future, bidirectional communication between the central and local sites will be ensured through appropriate solutions, that will require more meta-data related to communication. These developments are part of a new plan for the continuation of the program.

Theme 3. Implementation and Usage

BIRO Software *(V.Baglioni, U.Perugia, Italy)*

The BIRO system, available in the public domain as open source software through the GPL, will be intensely tested in the framework of the EUBIROD project. The BIRO Academy will be in charge of the dissemination of the approach and should facilitation adoption ot the software.
In this presentation, **Eng.Valentina Baglioni**, a professional software engineer from the University of Perugia, provides an overview on the usage of the software. The BIRO system runs on average PC Desktop/Notebook with at least 1Gb RAM, >200Gb Hard Disk and ADSL connection for use with Central Server. It has been successfully tested on Linux Fedora 10 and Microsoft Windows/Vista. To be properly run, it requires Java, R, Latex (Miktek), and an updated BIRO setup.
Eng. Baglioni reminds that BIRO users shall have a total of six well-structured datasets available to properly run the software: the "merge table", the "activity table", the "population table", the "diabetic population table", the "site header and profile" information, the "geographical table". Data fields of these tables must comply with the BIRO Common Dataset and XML Dictionary, whose structures are well described in the documentation of the BIRO project freely available at the official website.
In her brief, Valentina also presents the BIROBox as the main point of entry to the usage of the software to a user with average skills. A setup file is included with the main BIRO software bundle, which also creates the BIRO System directory structure. The setup contains all source code, libraries and documentation required for the BIRO System to operate.
The BIROBox includes an "adaptor" that automatically extracts a standardized BIRO export from local data. It also embodies a utility to load the export on a Postgres database and a launcher to configure and run the statistical engine, which ultimately creates local reports and formatted statistical tables. As a final screen, it includes a routine to safely transmit tables to the central BIRO server. The central server is operated by a BIRO administrator whose operational details are outside the scope of the current presentation.

Theme 3. Implementation and Usage

Discussion

In introducing the discussion, **Prof. Joseph Azzopardi** asks whether anything changed in Cyprus after the introduction of the diabetes register. Are doctors feeling that they are wasting their time, or do they see it as an interesting initiative for patients? According to **Vivie Traynor**, people have become aware that with the help of an electronic database, it is now possible to understand if patients attend the clinic regularly or not, something obvious that before was indeed not possible. That simple thing is now perceived to be very useful for all. **Dr.Mona Al Khawari**, Head of the Pediatric Diabetic Clinic at Al Amiri Hospital in Kuwait City, underlines that that experience is very important for those who are starting a register, e.g. the Kuwaiti colleagues. How long did it take to introduce the system, and what was the motivations that you induced into health professionals to do the job? According to **Vivie**, in the beginning people were not sure, but after a short while the same patients requested this, and they have become the best ambassadors for the adoption of BIRO. Certainly, it takes a long time to implement a system like this, particularly for the doctors. Some level of influence must be exerted, which is particularly difficult compared to the private sector, given that there is no economic incentive to do it.

Prof.Azzopardi asks how secure the system really is. **Peter Beck** underlines that, despite of all the work done, it still remains a good question. Sending aggregated data is of course less sensitive than other forms of communications. The Java communication technology in place is the same used for banks, so we are quite confident that the level of protection is high. However, to enhance security it is essential that the server is properly maintained (firewalls, etc). **Tania Di Iorio** underlines that the retention site (server location) complies with the EU Data Directive, so these measures are due to be implemented, particularly in Italy.

Dr.Michael Jecht makes the question on the number of characteristics to be transferred to the BIRO application. **Eng.Baglioni** clarifies that there are only few items that are mandatory, but of course a very small number of columns sent in aggregate tables would jeopardise the production of BIRO indicators. In other terms, that centre would only contribute to the BIRO report for few outputs. For **Simion Pruna**, that naturally happens in networks (e.g. ophtalmologists) that are mainly interesed in specific parameters. For **Peter**, there is a need to set options for choosing which source contributes to which indicator, based upon the quality and other issues. For **Carine de Beaufort**, all sources must be certified and agreed in advance, to understand what we compare each other. For **Fabrizio Carinci** this problem applies to centres that can have multiple ways to produce BIRO tables, due to an abundance of data sources.

Christian Awaraji from Dasman asks about electronic certificates (PKI), and who would distribute them. **Peter** answers that there will be no external authority, and the operation would be directly managed by the Consortium that will distribute them.

Scott Cunningham makes the question on whether the XML Adaptor producing the BIRO export is actually needed to do this task, or it may be skipped by centres using their own export software to do it. **Valentina** clarifies that, provided that the translation is made correctly, then it is also possible to directly create the local Postgres database and use it to launche the statistical engine. By the way, such

operation can be tricky and quite risky, as any mistakes would compromise the correct execution of the software and/or the production of accurate statistical reports.

Theme 4.

Regional Diabetes Registries for policy and practice

Theme 4. Regional Diabetes Registries for policy and practice

The relevance of diabetes policy in Kuwait, Yousuf Al Naifs *(Undersecretary of State, Ministry of Health, Kuwait)*

In this presentation, **Yousuf Al Naifs**, a high representative of the Kuwait Government in his capacity of Undersecretary of State for the Ministry of Health, introduces the audience to the relevance of the fight against diabetes in Kuwait, and highlights the various initiatives supported by the Ministry of Health to monitor quality of care and outcomes of a growing population affected by the disease in the country.

Theme 4. Regional Diabetes Registries for policy and practice

Address of the EU Presidency, Martin Vàvra *(Ambassador of the Czech Republic in Kuwait)*

In this brief introduction, **Martin Vàvra**, Ambassador of the Czech Republic in Kuwait, addresses the audience and congratulates with project partners for the initiative. The EUBIROD project, according to Martin, represents also an important opportunity for the hosting country to make a step ahead in fighting the disease more effectively and timely.

Theme 4. Regional Diabetes Registries for policy and practice

International collaboration for health policy, Enrico Granara *(Ambassador of Italy in Kuwait)*

In this brief introduction, **Dr. Enrico Granara**, Ambassador of the Italian Republic in Kuwait, confirms the interest of his government for the EUBIROD project as a relevant example of international cooperation. The importance of these initiatives lies in their very pragmatic approach, a potential success factor in a disease where environmental and lifestyle components may play a fundamental role in determining health outcomes.
In his talk, Dr.Granara emphasizes the potential benefits of the Mediterranean diet, as an important aspect of Italian lifestyle that the country would be eager to share with other countries, in Europe and beyond. Enrico congratulates with the University of Perugia for its coordinating role in this project, particularly since it provides the opportunity to the Italian Government and the European Commission to strengthen ties with Gulf Countries. That path must be further explored in new cooperating actions. Finally, Dr.Granara congratulates with the Directors of Dasman, noting the enormous contribution of the EUBIROD leader Prof.Massi Benedetti, an Italian in the capacity of Vice President of the IDF, Research Director at Dasman, and Coordinator of EU projects.

Theme 4. Regional Diabetes Registries for policy and practice

Diabetes in the Gulf Area *(A. Ben-Nakhi, Dasman Center, Kuwait)*

In this presentation, **Dr.Abdullah Ben-Nakhi**, Director General of the Dasman Center for the Research and Treatment of Diabetes, presents the situation of diabetes in Kuwait and the Gulf region.

The region includes 6 countries with the largest production of oil in the world. As a result, in the last 20 years, life expectancy increased 10 years, literacy 20%, as well as the prevalence of diabetes. According to the IDF Atlas, five countries in this region are in the top ten, and the situation will be the same in 2025. The same applies to glucose intolerance, a fundamental precursor of diabetes.

Dr. Ben-Nakhi presents several reports produced since the early nineties to document the prevalence of diabetes in these regions. Results show that the estimate is extremely variable, ranging between 10% and 30% for population older than 20 years. The latest study for Kuwait, the EMAN survey conducted in 2007, shows a prevalence of 16.7%, for the population over 30. These estimates raise enormous debate in the Gulf region and highlight an alarming situation for diabetes.

According to the evidence produced by EMAN, the high prevalence of risk factors provides a good explanation of the phenomenon: smoking, dietetic habits, inactivity, obesity, abnormal cholesterol are all huge problems in terms of the impact of modern lifestyle in Kuwait, as well as the whole region. Almost 60% of the population investigated has three or more risk factors present.

Concluding his talk, Abdullah provides the audience further information about cardiovascular events in the diabetic population, through the indirect means of the cardiovascular registry. It shows a significantly different rate of cardiovascular risk factors and hospital outcomes between diabetics and non diabetics, confirming that this area constitutes one of the priorities on which the Government is called to intervene.

Prevention control strategies are needed to target all major risk factors and break the dangerous cycle leading to diabetes complications. The diabetes registry represents an important step towards the realization of such strategies.

Theme 4. Regional Diabetes Registries for policy and practice

The EUBIROD project *(F. Carinci, Serectrix, Italy)*

The EUBIROD project, co-funded by the European Commission, started in September 2008 to implement a sustainable European Diabetes Register through the coordination of existing national/regional frameworks and the systematic use of the BIRO technology developed in the BIRO project.
In this presentation, **Dr.Fabrizio Carinci**, senior biostatistician, presents the main features of the project. A total of 22 participants from 20 European states, plus the Dasman Institute from Kuwait, will be connected through the system to safely collect aggregated data and produce systematic EU reports for diabetes indicators.
The workplan includes the following tasks: secure and privacy-safe data collection; development of epidemiological techniques to compute standardized diabetes indicators; development of a customized toolbox to facilitate the connection process and the transfer of technology; dissemination and training through the activity of BIRO Academy, which will establish an e-learning platform and residential training courses; evaluation, made by international experts, of completeness and information content of the statistical reports.
Fabrizio, who is involved in the project as a leader of the epidemiological analysis for Serectrix, describes how by August 2011, the project is planned to ensure the establishment of a stable network for data exchange at the international level and the creation of a common framework for standardized measurements whose users will be specifically trained. He anticipates that the main result arising from the project will be the annual production of the European Diabetes Report, consisting of an analysis of quality of care and outcomes in diabetes using standardized criteria on top of a database of over 500,000 subjects. The report will include a discussion of the results, targeted at providing valuable input for European policy makers, health care and scientific organization, citizens.
In his conclusions, Dr.Carinci remarks that the EUBIROD project further develops the platform established by BIRO and EUCID, whose results have raised the interest of the European Commission. The progress will advance the construction of a unique diabetes information system that can be used in Europe and beyond, realizing a possible model for the automatic production of global IDF reports.

Theme 4. Regional Diabetes Registries for policy and practice

The Tayside Diabetes Register *(R.Mc Alpine, U.Dundee, Scotland, UK)*

The Tayside area is located north of Edinburgh and is a good proxy for the population of Scotland, including a mix of agricultural and industrial lifestyles. The DARTS project conducted in 1996 was mainly an audit and research study aimed at monitoring quality of care for diabetic patients through electronic record linkage. In ten years, this study produced a wealth of knowledge on the topic and secured funds for the activity of a large team that is now managing not only the local network on a continuous basis, but the Scottish Diabetes Register.

In this presentation, **Ritchie McAlpine**, data facilitator for the Tayside Diabetes Network, briefs the results of such experience from a particular position in between the information technology group and the actual needs of real patients. Nowadays, the "SCI-DC" Collaboration includes data from about anything done on diabetic patients, from clinics to practices, biochemistry, demography, eye screening, etc., which is automatically transformed into audit tables.

Ritchie emphasizes how the main task of the network is to translate such huge mass of data into recommendations for policy making through the Scottish Diabetes Survey, information for the Scottish Diabetes Research Network, and reports for the patients through targeted information material. Sometimes the emerging picture is not encouraging, for instance we know that diabetic patients are increasing. However, the good news are that some of the major outcomes are also improving, and this can be also due to the better information available. That is not always true: Ritchie reports some entertaining story about data, e.g. a subgroup of patients that was reported as deceased, with an average"life after death" between 1-4 yrs, and a "resurrection rate" close to 0.01%.

According to McAlpine, this proves that inaccuracies do always exist, but if data systems are allowed to evolve, they can be improved and play a dramatic role in helping to fight diabetes.

Feedback directly provided to clinicians and patients allow to benchmark and optimize systems through a shared effort. In Tayside, the DARTS study evolved to become a sophisticated system used to support decisions and manage the disease. That has become an integral part of the care process.

By the way, the "garbage in, garbage out" principle always apply, and the Tayside team is always busy in removing the garbage when/where they find it. However - Ritchie concludes – it is also true that job never ends. The good side of the coin is that the more we know, the more we can change, and the more we can improve the outcomes of patients.

Theme 4. Regional Diabetes Registries for policy and practice

Diabetes Registry in Kuwait *(M. Massi Benedetti, Dasman Center, Kuwait)*

Success stories in the field of diabetes registers and health information may help understanding how to apply concepts to new areas, to provide better services, to improve results for the local population. However, success stories must be adapted to very specific situations, which in turn can rapidly change and naturally evolve towards other organizational structures.

In this presentation, **Prof.Massimo Massi Benedetti**, Scientific Coordinator of the BIRO/EUBIROD projects and Research Director at the Dasman Center for Research and Treatment of Diabetes, reminds us that it is not possible to buy success in diabetes registries.

According to Massimo, it is possible to import ideas, to extrapolate solutions, to understand problems, but it is not possible to directly import an entire system. Therefore, any interesting approach must be adapted to the local cultural environment and be tailored on the basis of the existing health system infrastructure.

In Kuwait, there is a great need to monitor the evolution of the disease and quality of care delivered to the local population as a fundamental prerequisite for the organization of optimal care programs. Success stories tell us that in such a case it is a must to have a national diabetes registry.

However, targets of this action are at different levels of the health system and require much more than simple epidemiological estimates. We must translate data into knowledge. According to Massimo, to realize the scope of a multilevel register, it is fundamental that the health information "biodiversity" is preserved, allowing the creation of the conditions required to use different databases without asking the adoption of a unique system. Furthermore, it is important that researchers/analysts understand that results cannot speak for themselves, and that they must be carefully interpreted to produce recommendations for policy makers.

To these ends, the technology developed by the BIRO Consortium seems to be relevant and provides a viable solution. The Dasman Centre has been recently given full mandate by the Ministry of Health to advance a plan for the implementation of the registry in Kuwait. From an initial review of information systems already in place, it appears that electronic medical records are used routinely and can be successfully linked to feed an electronic diabetes register. The Dasman Center is confident that the feasibility study just been initiated will end positively, indicating the road to success for the Kuwait register with the delivery of the final report, expected within six months from the present speech.

PHOTO GALLERY

F. Carinci introducing the BIRO Project

Round Table on Theme 1

Prof. Pruna presenting the BIRO Technology Transfer in Romania

V. Traynor presenting the BIRO Technology Transfer in Cyprus

P. Beck presenting integration and implementation in BIRO project

Prof. Massi Benedetti lecturing the subject of Diabetes Registry in Kuwait

Y. Al Naifs lecturing the subject of Diabetes policy in Kuwait

M. Vàvra talking about the EUBIROD initiative

E. Granara lecturing the subject of international collaboration for health policy

A. Ben-Nakhi lecturing the subject of Diabetes in the Gulf Area

M. Al-Khawari lecturing the subject of Kuwait Data for BIRO analysis

Audience