QUALITY DEVELOPMENT IN PERINATAL CARE: THE OBSQID PROJECT

Report on the Fifth WHO Workshop

Nof Ginossar, Israel
29 October – 1 November 1998
ABSTRACT

The obstetrical quality indicators and data collection (OBSQID) project for quality management and development in perinatal care involves an extensive network of health care authorities, researchers, professional associations and third-party payers throughout the WHO European Region. Previous workshops organized by the WHO Regional Office for Europe have focused on the development and refinement of two standardized, pan-European data collection tools: the case-based OBSQID basic information sheet and the OBSQID perinatal aggregated data sheet. At this Fifth Workshop, it was unanimously decided that in the coming years the project would strive to increase data reporting, to improve the validity of data, to identify centres demonstrating best practice and pair them with those expressing a need (i.e. establish twinning projects), and to improve perinatal outcomes throughout the European Region.

Keywords

PERINATAL CARE
OBSTETRICS
QUALITY OF HEALTH CARE
APPROPRIATE TECHNOLOGY
EUROPE
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Executive summary

There are approximately five million births annually in the European Region. Of these, more than 50,000 newborns suffer from complications that result in death or seriously reduce the quality of their later life. These adverse outcomes are often avoidable. They may be due for example to sub-optimal care, poor maternal and/or paternal nutrition, poor maternal and/or paternal wellbeing, or smoking during pregnancy. In addition, although obstetrical and perinatal care practices vary widely from country to country, some countries nevertheless exhibit similar outcomes. This may be due to sub-optimal use of resources in perinatal centres throughout the region.

The objective of the OBSQID project is to promote quality assessment and continuous perinatal quality of care development (QCD). This will be accomplished through the creation of a pan-European network of researchers, health care providers, professional associations, and third-party payers, as a first step. In 1993, these individuals met and reached a consensus—based on national experience—on a set of perinatal process and outcome indicators that are now collected in the WHO European Region using the OBSQID perinatal aggregated data (PAD) sheet (Annex E). The data are compiled anonymously in the database maintained at the Quality of Care and Technologies (QCT) Office at the WHO Regional Office for Europe in Copenhagen, Denmark (http://qct.who.dk/obsqid.htm). The centralization and continuous input of this aggregated data allows comparisons and benchmarking to be made across national borders as well as between regions and centres within individual nations. To date, the project has collected aggregated data on more than 13 million births in the European Region of WHO since 1992.

While the collection of aggregated, national level data is a mission of the OBSQID project, it is obvious that aggregated data cannot be collected unless valid, reliable means of collecting case-based data are in place. To meet this need, the OBSQID basic information sheet (BIS) was developed. The BIS is a one-page data sheet containing 50 process and outcome indicators (Annex D). The OBSQID project has developed a number of data management and analysis programmes that can be used to handle case-based data at collection nodes. However, data can also be submitted directly to the QCT office for analysis.

In the long term, it is envisaged that case-based data will be collected at local, regional or national level centres, and only aggregated data will be collected at WHO. This vertical processing of data will help to ensure its internal consistency, the timely availability of results, and facilitate opportunities for collaboration between clinics and between countries.

Since 1993, QCT has organized annual workshops where perinatal specialists in the fields of obstetrics, neonatology, public health, and telematics gather to share their experiences and ideas related to perinatal quality development and help further develop the OBSQID project objectives. So far, representatives from 44 of the 51 WHO/EURO Member States have been actively involved in these activities and workshops. In addition, a number of European perinatal medical societies have joined the OBSQID project. Most recently, the European Association of Perinatal Medicine (EAPM) and WHO have become partners.

At the Fifth Workshop, it was unanimously decided that in the coming years, the project will strive to increase data reporting, improve the validity of data, identify centres demonstrating best practice and pair them with centres expressing a need (i.e. establish twinning projects), and continue to contribute to the improvement of perinatal outcomes throughout the European Region.
Introduction

History of the OBSQID project

"By the year 2000, there should be structures and processes in all Member States to ensure continuous improvement in the quality of health care and appropriate development and use of health technologies. This target can be achieved through:

- Combined strategies for the assessment and promotion of the quality of care, the selection, development and proper use of appropriate technology, and the training of personnel;
- International collaboration and information exchange on assessment procedures, care standards, training and technology development."

— The WHO Health for All 2000, target 31, Quality of Care and Appropriate Technology

In the mid-1980s, the concept of using telematic information systems to collect perinatal data was developed. This came at a time when differences were being observed in maternal and child health throughout the European Region which could not be attributed to genetic or socioeconomic factors. It was suggested that the aggregation of perinatal data at local, regional, and national levels as well as timely data analysis, feedback and comparison of results could assist in promoting quality of care and improving perinatal outcomes.

In 1984, the European Office was given a special mandate by Member States to collect more extensive data on maternal and child health in the Region. A developmental strategy was initiated in 1986 by the Quality of Care and Technologies Programme and an action programme was subsequently carried out by the Office during the 1992–1993 biennium. An early version of a labour and delivery basic information sheet as well as a data collection software were developed as part of this action programme.

_The European Consensus Conference on Quality Indicators for Perinatal Care_
_Tübingen, Germany, 21–22 October 1993_

This conference was a joint effort between WHO/EURO, the Institute for Medical Information Processing (IMI) in Tübingen, Germany, and the Robert Bosch Foundation in Stuttgart, Germany. Perinatal experts in the fields of obstetrics, neonatology, public health, and telematics representing 25 EURO Member States participated in the meeting. Their main goal was to reach consensus on a set of key quality indicators based on existing practice which could be used for evaluating perinatal health care activities.

The main outcome of the meeting was the identification of 21 indicators proposed used by providers, national health authorities, and third-party contributors for evaluating quality and resource utilization in perinatal care. These indicators were compiled on the _OBSQID perinatal aggregated data (PAD) sheet._
The First Workshop on Quality Development in Perinatal Care
Hillerød, Denmark, 9–10 September 1994

The objectives of this conference were to discuss and evaluate the results of PAD pilot test (conducted October 1993–September 1994 at 29 centres and 18 national facilities) and to further refine the indicators. As a result, 23 indicators were finally agreed upon.\(^1\) PAD data collection activities were to continue through 1995.

The pilot revealed considerable differences in perinatal outcomes both between obstetric clinics/wards, countries and between regions within countries. To investigate why these differences existed participants recommended a case-based data sheet be developed to capturing data on individual patient encounters and processes carried out in relation to birth.

The Second Workshop on Quality Development in Perinatal Care
Trieste, Italy, 6–8 October 1995

This workshop was organized by the Instituto per L’Infanzia of the Bureau for International Health (WHO collaborating centre) in connection with the WHO/Euro course, *Perinatal care: planning for appropriate equipment*. The objectives were to present the results of 1993–1994 PAD pilot testing, create a preliminary version of the *OBSQID basic information sheet (BIS)* for case-based data, and introduce the concept of benchmarking as a tool for QCD.

The OBSQID BIS evolved into a one-page form containing over 50 process and outcome variables related to the perinatal period. It was piloted in September, 1996 in 11 clinics in 8 countries and data on more than 1200 deliveries was collected.

The Third Workshop on Quality Development in Perinatal Care
Trieste, Italy, 18–20 October 1996

The Third Workshop focused on reviewing the data from the 1996 BIS pilot, discussing the advantages and disadvantages of OBSQID data collection systems, sharing experiences with data collection activities from various European countries, and proposing a logo for the OBSQID project. The BIS variables and definitions were finalized. It was decided that indicators on maternal and fetal wellbeing would be included in data collection activities, that guidelines for the establishment of national perinatal QCD policies in member countries be developed, and that twinning projects be established.

The CARAK BIS

In December 1996, a special version of the OBSQID BIS which included data on family planning was presented at a meeting in Tashkent, Uzbekistan, attended by representatives from Azerbaijan, Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan and Uzbekistan. This BIS was produced in coordination with the Sexuality and Family Health Programme at WHO/Euro. The BIS was presented to representatives of pilot districts from the central Asian republics, Azerbaijan and Kazakhstan (CARAK) with an invitation to test the tool at their clinics. The

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\(^1\) The original "perinatal mortality" indicator was divided into antenatal death (after 27 weeks), fetal death in-partu, and early neonatal mortality (i.e. death within 0–6 days after birth, reflecting different responsibilities in particular stressing the responsibility of the obstetrician in intrapartum death.)
resulting pilot test collected data on approximately 1500 births from five of the six CARAK countries.

*The Fourth Workshop on Quality Development in Perinatal Care*
*Poznan, Poland, 23–25 October 1997*

The goals of the meeting were to discuss the results of the second OBSQID BIS pilot conducted 15 May–15 June 1997, assess the need for further modifications of BIS variables, examine perinatal outcomes from recently collected PAD data, and increase twinning project activities. Participants also agreed on an OBSQID logo.

Recommendations were made to produce a separate neonatal BIS sheet because participants felt the existing BIS did not adequately record neonatology issues. In addition, working groups discussed specific sections of the BIS (ultrasonography, anaesthesia, wellbeing, blood transfusion, diabetes, and neonatology) and how the concepts and tools of OBSQID can be integrated into existing national data collection systems at the local, regional and national levels.

**Objectives of the Fifth Workshop on Quality Development in Perinatal Care**

The main goals of the Fifth Workshop were to:

- Examine the accomplishments of the first five years of the Project and critically review its successes and failures.
- Examine WHO and country-specific models for data collection and management.
- Discuss the outcomes of case-based data collection activities using the OBSQID BIS as it was revised at the Fourth Workshop with a view to establishing twinning projects.
- Present the activities conducted under the twinning projects with an emphasis on the results and outcomes as demonstrated by case-based data.
- Examine the implementation of electronic patient records (EPR) using the EPI-INFO data registration system, and discuss experiences with using this tool. In centres where no such facilities exist, solutions will be sought to introduce EPR systems in these centres.
- Discuss the progress made in developing the neonatal BIS and its links to the existing obstetrical BIS, as well as the development of case-based data collection sheets within other specialities. Participants will suggest ways to promote the use of such sheets.
- Provide participants with an opportunity to share their experiences and ideas related to the development of quality in perinatal care practices, outcomes, and technologies.
- Discuss how countries can develop national QCD policies based on existing perinatal QCD programmes.
- Consider how patient rights and confidentiality may be affected by clinical databases.
- Outline future goals for the project.
- Confirm the formal collaboration between WHO/EAPM and initiate collaboration with other potential partners.
Proceedings

Opening session

Drs Moshe Hod (host), Boaz Lev (Deputy Director, General Ministry of Health) and A. Samueloff (Chairman, Israeli Perinatal Society) welcomed the workshop participants. Dr Hod gave a brief history of the Rabin Medical Center’s involvement with the OBSQID project.

Dr Kirsten Staehr Johansen of the Quality of Care and Technologies (QCT) Office (WHO/EURO), extended a warm welcome on behalf of the World Health Organization. She explained that WHO/headquarters is currently identifying global health problems to target in the future. In this connection, depression has been identified as a major problem which is now being addressed within the scope of both the OBSQID and other QCT projects, and data on maternal as well as paternal wellbeing and violence during pregnancy is being collected.

Dr Zion Ben Rafael (Honorary Chairman) emphasized that one cannot improve the quality of health care without collecting and standardizing data on clinical practices. He stressed the role of data for effective policy-making and pointed out that sharing data and comparing outcomes within and across national borders facilitates benchmarking and quality improvement.

Dr Cihat Sen (Rapporteur) gave a general welcoming address to the Workshop participants.

Dr Karel Marsal of the EAPM (Head, Study Group on the Standardisation of Birth and Death Certificates) gave a brief history of the study group which initially started with the goal of creating a unique set of standard perinatal indicators for Europe. The group has requested copies of perinatal data forms from each of the EAPM member countries and received forms from 14 of the 23 members. The forms were compared and an attempt was made to design a perinatal health form containing a standard set of European perinatal indicators. The Study Group has encountered difficulties in motivating ministries of health to replace their national data collection forms with the EAPM form. Thus, the Group decided to join the OBSQID project in order to help accomplish its goal.

Dr Gunilla Lindmark of the FIGO (Chairperson, Committee on Perinatal Health) explained that the goals of her committee are to develop a globally useful set of perinatal indicators and standardize the definitions for each indicator. The committee is composed of five people and, because of its small size, it recognizes the importance of linking with organizations with similar goals. The committee’s main achievement has been the collection of data forms from associations affiliated with the FIGO. In the future, the committee plans to develop perinatal data forms for use in rural clinics and hospitals in developing countries.

Dr Kirsten Staehr Johansen gave a brief history of the OBSQID project. She explained that the main tenet of the project is the notion that “success comes from within the individual” – in this case, from medical professionals themselves. She pointed out that there is no profession in history where members have undergone the task of self-evaluation and comparison with peers and have not improved their services as a result. She commented that the goal of all attending the meeting must be a happy family, fathers, mothers and children, with the fewest medical interventions, an increase in the number of twinning projects, and improved perinatal outcomes. With respect to twinning projects, she made the point that success is made through the actions of people and is not necessarily dependent on money. Thus, model twinning projects are those that strive to improve outcomes through the exchange of knowledge first, and technology second.
WHO/EURO data collection and analysis tools

After each of the presentations below, the speakers were available to participants to demonstrate their tools to small groups and hold discussion sessions. Participants circulated among the rooms and were invited to comment on the tools and make suggestions. They also discussed ways of integrating these data collection tools and systems into the data collection and analysis systems in use in their own countries or sites.

EPI-INFO: Introduction to the tool
Dr Dina Pfeifer

Description of software

This is a shareware software which means there are no costs except for downloading the program. The software was produced by the U.S. Centers for Disease Control and WHO and has been available since 1980. The software file is not too big and therefore does not require much memory to run. Version 6 is the latest available version. This software is DOS-based which means the graphical capabilities are not very extensive.

Why use it?

The main reasons for using this software are that it is easy to learn, there are few variables, it does not require a vast knowledge of statistics, and can be used by people who have limited computer experience.

Level of analysis

EPI-INFO is not as sophisticated as SAS or SPSS. It was designed to be used as a field epidemiology software program.

The Israeli experience with EPI-INFO implementation
Dr Rony Chen

Dr Chen presented his personal experience with the OBSQID project and that of the Department of Obstetrics and Gynaecology at the Rabin Medical Center in Petah Tikva, Israel. Dr Chen was first introduced to the project during the OBSQID BIS Pilot Study in June, 1997, in which obstetrical data were gathered during a one-month period. Then, in October 1997, he was sent on behalf of the department to participate in the Fourth Workshop held in Poznan, Poland. There, he learned how data were to be collected using the OBSQID BIS. He also learned about several data analysis methods including EPI-INFO which appeared to be most appropriate for use in his department.

In November 1997, Dr Chen was formally instructed in the use EPI-INFO by Dr Dina Pfeifer in Zagreb, Croatia. Although the department was aware of several problems in adapting EPI-INFO (such as the size of the department and the availability of equipment), it was highly motivated to succeed. Several computer terminals were prepared in the labour and delivery room, high risk unit, and clinic. Then EPI-INFO was installed and connected to the hospital computer network.

Before describing the process of data collection, Dr Chen explained how women are admitted to the labour and delivery floor. First he noted that the Rabin Medical Center handles 6500 deliveries
each year. A woman’s first encounter with the medical staff is in the admission room. The
physician in charge performs the history and physical examination and a triage is done. Women
in active labour are admitted to the labour and delivery room. A new patient file is issued for
women who are to be hospitalized in the high risk pregnancy department. A separate patient file
is issued for women who are to be followed at the ambulatory high risk clinic.

Following delivery, pertinent data concerning the labour and delivery is gathered. The woman is
admitted to the maternity unit and the newborn to the neonatal unit. In the case of premature
neonates or any complicated labour requiring special care, the newborn is admitted to the
neonatal intensive care unit. From then on, the process of data collection is continued separately
in the different units. For each woman, data from the labour and delivery are combined with
those from the maternity unit. Data concerning the neonate are collected and summarized by the
paediatricians.

Description of the EPI-INFO implementation project
During the first half of 1998, the BIS was piloted in the obstetrical department. Data were
recorded for every birth during those six months. The goals of the pilot were to identify problems
with this data collection method, ensure the quality of the data entered, and present a model for
constructing regional, national, and international BIS’s. Analysis was done at the Israeli Centre
for Statistical Analysis.

Data were collected on 2374 patients. Information on maternal education level, reproductive
history (induced and spontaneous abortions, ectopic pregnancies, vaginal deliveries, Caesarean
sections, stillbirths, live births, preterm deliveries, and neonatal deaths), and selected maternal
variables (maternal age, height, weight, and weight gain) were recorded. Data were also
collected on maternal habits such as smoking, alcohol use, and drug abuse. Current pregnancy
history items were recorded such as the total number of sonographic scans and the gestational
age at the first and last ultrasound. Pathologic indices that were recorded include breech
presentation, transverse lie, therapeutic abortion, threatened premature labour, antepartum
haemorrhage, gestational hypertension, pre-eclampsia, suspected intrauterine growth retardation
(IUGR), in vitro fertilization/artificial insemination (IVF/ART), blood group immunization,
infection, and cardiovascular disease. Types of labour were stratified into spontaneous labour,
induced, labour, and planned Caesarean section (CS). Delivery indicators included type of birth
(spontaneous, forceps, vacuum, assisted breech, CS before labour elective and acute, CS during
labour elective and acute), gestational age at delivery, number of deliveries (singlet, twins, and
triplets, all stratified by means of conception, type of birth, presentation, and birth weight).
Special conditions such as premature rupture of membranes (PROM), episiotomies, lacerations,
hysterectomies, retained placenta, bleeding, and shoulder dystocia were recorded. Infant
pathologies were recorded (hyperbilirubinemia, respiratory conditions including respiratory
disease syndrome (RDS), sepsis, seizures, transfusions, etc.) as was the distribution of total and
neonatal deaths.

Analysis
A trial to collect the data directly into the EPI-INFO program failed for a number of reasons.
First, not all units had computer terminals to access EPI-INFO. In the stations with a computer,
there were practical problems with data collection. Usually, only part of the data was available
from antenatal follow-up or staff descriptions of labour and delivery. This information was often
incomplete necessitating additional questioning of the woman. With the tremendous daily
workload in labour and delivery wards, the data collection process became very time consuming and practically impossible to carry out accurately.

At this stage, we decided that all BIS’s would be filled out manually and entered into the computer database at a later time. This gave the best cooperation from the medical staff however, it still took four months for the idea to be accepted and carried out by the personnel in charge. The BIS’s were rarely filled out completely and missing data were often added retrospectively when it was available from archived patient files. Unfortunately some information was consistently unavailable because it was not asked for upon encounters with the woman (e.g. total number of sonographs and maternal wellbeing following delivery). It was finally decided to enter the data into a friendlier computer program, SAS, which is compatible with Microsoft Windows and allows direct statistical analysis. The members of the ICDC staff were responsible for computerizing the data and for statistical analysis.

Conclusion

The EPI-INFO data collecting system have proved impractical for the daily work in ICDC because it does not alleviate the need for manual data collection. Electronic patient files will probably give the best results for future perinatal data collection efforts. The department is currently moving towards universal, computerized patient files. Computerization should enable us to complete the BIS automatically and produce an accurate, complete database.

Operational management system in an obstetric service
Dr Baruch Marganitt

Dr Marganitt presented an Israeli approach to data collection and quality management called the Medical Operational Management System (MOMS). This system is under development at the Rabin Medical Center. The presentation focused on its use in the obstetrical department, however it can be used in any hospital department.

The obstetrical department is a hive of activity where a number of different activities of varying complexity are undertaken at the same time. To ensure that patients receive clinical and cost-effective management in this chaotic arena, it is crucial that standards of clinical and administrative care conform to best known clinical and administrative practices. MOMS was designed to ensure that this happens by taking account of three important issues: quality assurance, risk management, and cost-containment.

At present, there are no real tools in Israel to support real-time management. MOMS aims to provide such tools and, in so doing, avoid the errors inherent in retrospective analyses. MOMS’s also aims to eliminate the hassles of data collection often referred to as data agony: collection, reporting, documentation, analysis, integration, presentation, interpretation, decision, and action. It has the added advantage that it can be run on ordinary PCs.

MOMS functions at three main levels. First, it integrates data from several clinical sources. Second, it allows data to be collected during routine work thus offsetting the need to input data at a later stage. Third, it allows one to link information from other units/departments. For example, if the obstetric system is linked to the pharmacy system, the pharmacy will know when drugs are being prescribed or changed for a given patient. This also ensures automatic report generation
and data warehousing. Obviously, this cannot occur where computers and software are incompatible.

Previously, terminals were set up in each individual department and ran on their own private systems. This meant data were localized within departments but not sent to one central department for analysis and comparison. MOMS aims to provide some sort of vertical processing so that all data flow to one central person or department.

Medical Smart Card and its application in perinatal medicine
Dr Esther Saiag

Western culture today is a card-conscious society. Used as a financial medium at first, the card technology has now been implemented in almost all sectors of economic and social life. In the health sector, the overall landscape of health card applications has been growing tremendously. The increasing use of information systems in health care for administration, billing and medical record keeping, brought about the need for smart card technology that will qualify both for medical and administrative issues. Medical smart cards (MSC) are given to a patient who then becomes responsible for taking care of them and presenting them at the appropriate time and place. The application of MSC is highly relevant in perinatology – a field characterized by frequent visits to different locations during pregnancy, high incidence of subsequent pregnancies, relevance of previous history to current pregnancy, frequent occurrence of unexpected emergencies, necessity of awareness of high risk (e.g. DM, TH) for provision of appropriate management. Indeed, the MSC can serve as a tool for the availability of medical data at any time, quality of care, pan-European database aggregation, and a base for standardization. The process of MSC implementation in perinatology can be as follows: a medical smart card will be issued for the pregnant woman on her first visit to a medical authority. The data aggregated during her follow-up visits to different caretakers (in the community/hospital/consultation units such as labs, US, etc.) will be stored in the card chip. This data can then serve as a basis including those in the delivery room, during the current pregnancy as well as the successive ones. In addition, these “basic information sheets” (BIS) of pregnant women from throughout Europe can serve as the basis for the establishment of a Pan-European aggregated database (PAD). Likewise, specific interest groups (such as diabetic, hypertensive, neonatal, etc.) can build specific PADs. In summary, the application of MSC in perinatology can serve as a practical, inexpensive tool for establishing a globally useful perinatal data set, for the sake of better perinatal quality of care.

Paper-based data collection, fax submission, PAD and internet data analysis options
Mr Visti Juncher

Mr Juncher gave a brief on-line presentation of the OBSQID home page which is located at http://qct.who.dk/obsqid.htm. He pointed out the main features of the site:

- description of the OBSQID project;
- link for obtaining a copy of the OBSQID perinatal aggregated data sheet in English or Russian;
- link for submitting OBSQID PAD data;
- sample OBSQID BIS;
- link for requesting an OBSQID BIS with your own personal code;
- link to the OBSQID BIS in EPI-INFO format;
- ability to browse available data and request data analysis;
- OBSQID newsletters available for downloading.

A graphic interpretation of all submitted data is made available to the public through [http://qct.who.dk/padq.htm](http://qct.who.dk/padq.htm). In accordance with project policies, the identity of sites/countries submitting data remains confidential. Each data submitter at local, regional or national level is given a unique code known only to the submitter and to WHO.

Plans for the future include automatic receipt and handling of both OBSQID EPI-INFO files and the new Diabetes in Pregnancy BIS. In both cases, files should be sent as an e-mail attachment to obsqid@qct.who.dk. When the service is operational, it will be announced on the home page.

**Practical experiences using the OBSQID BIS**

| The United Kingdom  
Dr Philip Banfield |

There are a number of practical, administrative, technological, and professional problems with using the OBSQID BIS in the United Kingdom. The main problem is that in the United Kingdom, there are many mandatory obstetrical records that must be filled out before one gets to the OBSQID BIS. In spite of this, they decided to participate in the 1998 OBSQID BIS project. Five hundred OBSQID BIS data sheets were collected over a two-month period. When the BIS sheets were reviewed, it was obvious that the quality of the data was quite poor. In spite of this, attempts were made to enter the data into EPI-INFO for analysis, but the system crashed! In the end, they decided not to submit the data. Instead, Dr Banfield highlighted some of the specific difficulties encountered with the BIS data collection effort:

**Difficulties with filling out OBSQID BIS**

1. Not adequate for recording ultrasound results such as malformations.
2. Certain items are hard to fill out in the context of a real patient encounter. Some were not clearly defined. Other items are not detailed enough to provide data which truly reflect the quality of care (e.g. episiotomies, lacerations).
3. There was some confusion about the definitions of certain items such as hypertension, pre-eclampsia, and eclampsia.
4. There is no way to code for certain important pre-existing maternal conditions such as schizophrenia.
5. Lots of items were left blank in this pilot. Perhaps that reflects the fact that the staff needed additional training on how to fill out the forms. However, it may also represent flaws with the form itself.
6. There is no way to record data that are relevant to the perinatal period but discovered later. For example, children who are found to have cerebral palsy or mental retardation due to perinatal events should somehow be captured on the case-based sheet.
Realization of the OBSQID Project in Russia
Dr Elena Charapova, Mother and Child Health Dept., Public Health Institute, Moscow
Mrs Elena Zemlianova, Medical Demography Dept., Public Health Institute, Moscow

In 1993, Russia officially agreed with international criteria for recording live and stillbirths as recommended by the World Health Organization. In practice, the process of adopting these criteria presented a number of challenges. It required modifying legislation concerning the health care organization in Russia, reproductive health and reproductive rights, and social guaranties during pregnancy and the post-delivery period. At the same time, it required modifying the state system for the collection and publication of statistical data.

Preliminary analysis showed that the introduction of these new criteria would lead to a growth in figures for perinatal mortality, stillbirths and early neonatal mortality (Table 1).

Table 1. Perinatal losses in Russia on the basis of new criteria of live and stillbirths

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</thead>
<tbody>
<tr>
<td>Perinatal mortality per 1000 live/stillbirths including very low birth weight babies between 500–999 grams</td>
<td>32.0</td>
<td>34.5</td>
<td>33.7</td>
<td>32.4</td>
<td>29.8</td>
<td>29.8</td>
<td>29.9</td>
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<td>Birth weight over 1000 grams</td>
<td>17.8</td>
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<td>17.7</td>
<td>17.4</td>
<td>16.1</td>
<td>16.0</td>
<td>15.8</td>
</tr>
<tr>
<td>Stillbirths per 1000 live/stillbirths including very low birth weight 500–999 grams</td>
<td>22.9</td>
<td>25.4</td>
<td>23.7</td>
<td>22.2</td>
<td>20.5</td>
<td>21.0</td>
<td>21.4</td>
</tr>
<tr>
<td>Birth weight over 1000 grams</td>
<td>8.8</td>
<td>8.4</td>
<td>8.0</td>
<td>7.9</td>
<td>7.6</td>
<td>7.9</td>
<td>8.1</td>
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<tr>
<td>Early neonatal mortality per 1000 live births incl. very low birth weight 500–999 grams</td>
<td>9.3</td>
<td>9.3</td>
<td>10.2</td>
<td>10.4</td>
<td>9.5</td>
<td>9.0</td>
<td>8.7</td>
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<tr>
<td>Birth weight over 1000 grams</td>
<td>9.1</td>
<td>9.2</td>
<td>9.8</td>
<td>9.6</td>
<td>8.6</td>
<td>8.2</td>
<td>7.8</td>
</tr>
</tbody>
</table>

The analysis of the data in Table 1 shows that perinatal mortality increased 1.8–1.9 times and stillbirths 2.6–3.0 times. However, the changes in early neonatal mortality rates were not remarkable when we included very low birth weight babies (500–999 grams) in the calculations.

The transition to using international criteria for live and stillbirths in Russia is incomplete. We recognize, however that adopting WHO criteria will allow us to participate in international perinatal quality assurance efforts.

Introducing the OBSQID BIS

Due to the socioeconomic crisis and decentralization of the Russian health care system, the introduction of the OBSQID BIS seemed very problematic. Nevertheless, an attempt was made to introduce the OBSQID BIS in five clinics in Moscow, Ulianovsk, Murmansk, Tatarstan, and Chuvash. The analysis of the data made a subsequent proposal to the Ministry of Health to change the national data form, more persuasive. Modifications were recommended for the sections on current pregnancy, delivery, and newborn history. Modifications were also recommended in medical care protocols and other statistical report forms. The inclusion of indicators recommended by the WHO as well as some new indicators of specific importance to Russia was requested. As a result, new statistical forms have been introduced in all Russian territories.
OBSOJD BIS data analysis

At present, BIS information on all cases of perinatal deaths (306 cases) is available. Analysis of these cases has made it possible to evaluate the role of social, medical and behavioural factors on the improvement of prenatal and perinatal care. The characteristics of women with perinatal deaths were shown in a series of figures. A summary of the data is as follows:

- **Marital status:** 85.9% married and 14.1% single.
- **Mother's age:** 17% were age 19 or under, 57% were between the ages of 20–29, 24% were between the ages of 30–39, and 2% were over the age of 40.
- **Educational level:** 3% of women had received primary level education, 80% had completed secondary school, and 17% had a university education.
- **Previous outcomes:** 93% had a history of a previous live born infant while 7% had a history of a stillborn infant.
- **Reproductive events:** 57% had a history of Caesarean section, 34% had a previous history of vaginal delivery, 9% had a previous history of spontaneous abortion. The rate of preterm deliveries was 11.2%. Congenital malformations as a cause of early neonatal death was 3.2%.
- **Prenatal care history:** 93.1% percent of pregnant woman received prenatal care. Of these, 57.8% saw an obstetrician before 12 weeks of gestation, 31.7% between 13–27 weeks, and 3.6% saw one after 28 weeks.
- **Maternal perinatal mortality:** Among women with perinatal deaths, 33.5% were smokers, 2.5% had a history of alcohol abuse, 1.6% had a history of narcotics abuse, and 4.8% suffered from physical violence. According to our study only 18% of women with perinatal death did not have any health disorders.
- **Present pregnancy pathology:** 53% had gestational hypertension, 39% had threatened premature labour, 5% has placenta abruption, and 1% each had pre-eclampsia/eclampsia, placenta previa, and antepartum haemorrhage.
- **Fetal pathology:** 15.4% of fetuses were suspected of having intrauterine growth retardation while under medical supervision.
- **Maternal co-morbidities:** Cardiovascular diseases, infections of the urogenital system, and obesity were the most often registered somatic disorders during pregnancy. Only 2.6% of pregnancies were complicated by diabetes (all with NIDDM).
- **Anaemia:** One third of pregnant women were diagnosed with anaemia. This is a very serious problem for Russia because the rate is so high and has grown 2.5 times since the beginning of the 1990s. The problem is intensified by late diagnosis and treatment difficulties in the later stages of pregnancy.
- **Congenital malformations:** Only 44.7% (56.9% – urban, 31.0% – rural) of women with perinatal deaths had undergone ultrasound examinations. This situation has resulted in poor diagnosis of congenital malformations. Antenatal diagnosis of congenital malformations as a cause of perinatal death occurred in 3.3% of cases although expert opinion says this rate could actually be as high as 7.2%. After autopsy, the rate of congenital malformations as a cause of perinatal death rose to 15.7%.
- **Deliveries:** 81% were spontaneous, 16% were by Caesarean section, 2% were forceps deliveries, and 1% were assisted breech deliveries. It is necessary to note that the proportion of Caesarean sections in towns and cities was 1.4 times higher than in rural territories. Most of Caesarean sections were performed for acute medical reasons.
- **Gestational age at delivery**: 45% were full term (38–40 weeks), 25% were preterm between 32–37 weeks, 23% were preterm under 32 weeks, and 7% were post-dates between 41–42 weeks. When perinatal deaths are stratified according to gestational age at delivery, there is a rather high contribution from preterm deliveries (48%). Very often, malpresentation of the fetus was the cause of perinatal death. Nevertheless, Caesarean sections in cases of malpresentation were made in 13.0% of cases. One third of fetuses with such pathology died intrapartum. Most of those perinatal deaths could have been prevented by Caesarean section.

- **Apgar scores**: Live births with Apgar scores of 6 or less at 1 minute were 82.6% of all live births.

- **Perinatal deaths**: According to expert opinion, about 27.8% of deaths could have been prevented by improvements in prenatal care, more appropriate obstetrical care, more organizational measures in obstetric care development especially in rural areas, and improvements in intensive therapy for the newborn. At the same time, we must recognize that social and behavioural factors also play an essential role here. This problem can be solved, in part, by developing special educational programmes for both pregnant women and non-pregnant women of childbearing age.

- **Cause of death**: 41% were due to birth asphyxia, 21% to respiratory distress syndrome, 15% to congenital malformations, 14% to birth trauma, 3% to infection, and 6% to other causes.

**Conclusions**

The introduction of the OBSQID BIS led to the realization that there are a lot of important indicators which are not currently collected universally in Russia which can help to improve prenatal and perinatal care services and outcomes. At the same time, there are some indicators with specific relevance to the Russian experience which need to be collected such as the percent of pregnant women who participate in prophylactic programs; the percent of disorders diagnosed before delivery; registration of anaemia of pregnancy; amount NICU care and possibilities for fetal or neonatal transport especially in rural areas; and, social factors such as family income, employment, harmful occupational factors, and living conditions. Some of above mentioned indicators have been included in the new statistical forms and primary medical documents which were approved at the state level.

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**The Former Yugoslav Republic of Macedonia**

**Professor Jovan Tofoski**

The Former Yugoslav Republic of Macedonia has had computerized patients records since 1983. In the city of Skopje, the Department of Obstetrics has a computerized patient questionnaire that contains 117 data items. This questionnaire contains most of the items currently on the OBSQID BIS. However, some of the definitions used on the Skopje data sheet differ from those used on the OBSQID data sheets.

As a result of the experiences in Skopje, a number of problems with case-based data collection have been identified and some local solutions have been devised. First, it is crucial that the sheets be filled out properly. In order to ensure that this occurs, it is important that the people recording the data feel that their efforts are not in vain. To ensure the reliability of the data, one
person was assigned the task of comparing medical records with their corresponding computer file then filling in the case-based forms. This reduces the likelihood that errors were made.

Second, there have been problems getting physicians to fill out the case-based forms at both the local and regional levels. Doctors and midwives must be educated about the importance of the data collection process. They must be trained how to use the forms and they must be aware of the definitions for each data item.

It is important that the results of data collection efforts be presented from time to time. This allows medical personnel from different centres to not only view the data and outcomes from their site, but to also compare their performance with that of other facilities. Of note, the medical staff in The Former Yugoslav Republic of Macedonia does not like having anonymity about the sites contributing data.

The fourth problem is that the computers are old and are not linked via a network system. Therefore, every couple of months someone must drive to each hospital to collect the data. Only then is it compiled. This means that available data are always out-of-date. It is important that someone from each department (e.g. the department chief) be responsible for ensuring that the data are collected regularly and transferred to the regional and national level.

The Czech Republic
Dr Petr Velebil

The Czech Republic has a long history of collecting case-based data. Since 1948, data on perinatal deaths have been collected. Since 1981, data on high-risk pregnancies have been recorded. Although BIS-like questionnaires on both the parturient and the newborn have been in use since 1991, the Czech Republic has participated in pilot projects aimed at testing OBSQID data collection tools.

The OBSQID BIS and Czech data collection forms contain many of the same variables. The Czech case-based data form records data on the mother (e.g. highest educational level attained, age), reproductive history (e.g. outcomes of previous pregnancies), and current pregnancy (e.g. number of prenatal visits, number of ultrasound exams). In the section on current pregnancy, a coding system is used to record pregnancy complications which, unfortunately introduces a source of errors and omissions. There is also a section for recording data on the delivery (e.g. gestational age at delivery, mode of delivery, attendant at delivery, blood loss, maternal status at discharge). This section is much more detailed on the Czech form but again uses a complicated coding system for special conditions which introduces a source of recording errors. The infant section records items such as date of birth, status at delivery, birth weight, length, sex, and status at discharge. We note that there are fewer variables in this section than on the neonatal BIS, but we have had difficulty linking them.

There are a number of important variables that the Czech form does not capture. For example, neither neonatal deaths nor wellbeing items are on the Czech form (although consumer satisfaction levels have been estimated in separate surveys). In addition, information on maternal height, weight, and weight gain are not on the national form. The OBSQID BIS permits better recording of pregnancy complications, special conditions, and infant information. It is the hope to combine the Czech national form with the OBSQID BIS to come up with an improved data
collection tool for national use which will also allow us to join the international effort to standardize perinatal data.

Perinatal care in Europe: what are you doing in your country for data collection

**Israeli National Perinatal Data Systems**  
**Ms Pnina Zadka, Health, Social and Welfare Statistics, Central Bureau of Statistics**

**Data sources**

National databases regarding vital and morbid events are generally collected, processed and published by the Central Bureau of Statistics (CBS) in the Israeli National Statistical Office. Perinatal data sources at the CBS include births (live and stillbirths); deaths (maternal and infant); hospitalization (deliveries, pregnant women and newborns); and morbid events (congenital malformations, legal abortions (spontaneous and induced)).

Data are based on compulsory reporting systems which are mandated by law. All data are recorded based on a unique ID number granted to all Israeli residents upon birth or immigration. This ID number enables one to link events involving an individual which may be recorded in different databases.

Confidentiality is very strict. Only unidentified, aggregated data are published or disseminated. The CBS, as stated in the statistics law, developed query procedures to insure completeness of reporting.

The main disadvantage of these systems is their rigidity. Changes in reporting schemes or reporting forms involve legal actions and organizational changes. Another flaw is the lag in time between the analysis of data and its publication and availability to the public.

**Perinatal outcome trends in the last twenty years**

Fertility rates in Israel have stabilized in the last two decades at 2.8 children per woman which is a relatively high rate for an industrialized country. Less than 0.1% of deliveries occurred outside of hospitals during this period and maternal death rates were, on the average, 4 per 100,000 births. Deliveries to mothers over 40 years are increasing and amounted 2% of all deliveries in 1996. Multiple pregnancies have doubled from 1% in 1976 to 2% in 1996. 10% of babies are of 6+ birth order. About 1% of newborns weighed less than 1500 grams and those weighing 1500–2499 grams increased from 5% in 1976 to almost 7% in 1996.

Despite the increase in high risk births, perinatal mortality decreased substantially. The stillbirth rate dropped from 9 to less than 4 per 1000 births. Early neonatal deaths dropped from 10 to 2.5 per 1000 live births. The decrease in perinatal death rates over the whole perinatal life span indicates improvement in pregnancy care as well as obstetric and neonatal care.

**The Italian experience**  
**Dr Federico Mecacci and Dr Giorgio Mello**

In Italy, the collection of data regarding pregnancy, delivery and puerperium is based on two different systems: the diagnosis-related group (DRG), and the birth certification by the attending physicians (BCAP).
The DRG is a system of classification that includes diagnosis and therapy of each clinical case. It was created to achieve two main aims: to evaluate the payment by the State to participating hospitals and to evaluate quality care and rate the participating structures. The DRG also provides a limited source of data that can be used for statistical evaluation. When the patient is discharged, the attending physicians completes a form that includes all the data collected at hospital admission, diagnosis and treatment during hospital stay and that is the tool for transmitting data to the DRG. Hence, most of the information available from the DRG is paper-based. The data include date, time and type of admission, demographic characteristics, primary and related diagnoses; complications, operations performed, delivery and diagnostic procedures carried out.

Italian BCAP is an alternative system for harvesting perinatal data. The certificate was first conceived as a means of registering the birth of a child; it contained a few basic data. Thereafter, it has been modified by each Region in order to provide more detailed information regarding obstetric history, current pregnancy, delivery and name, weight, length, sex and physical condition of the newborn. The BCAP data are submitted to the Town Hall Registry Office, to the local office of the National Health System and to the National Institute of Statistics (ISTAT). Unfortunately, our National Institute of Statistics requires at least three years before any detailed analysis can be made. This is because our data are still paper-based, from paper the data must be transposed into computer-based information and information is collected only once a year.

In 1994 the overall rate of stillbirths in Italy was 0.44%. Among the major causes of death were: placental pathology which accounts for about one-third, umbilical cord pathology (16.4%) and acute or chronic fetal distress (12.2%). Interestingly, the data relating to our region (Tuscany) match those observed at the national level. This may indicate that Tuscany is representative of the whole country. It is also important to note that there is a certain degree of approximation involved in the classification of the causes of stillbirth. On the one hand, this inability to arrive at a precise diagnosis might reflect an intrinsic difficulty in classifying disorders that often overlap; on the other hand this lack of defined data highlights the need for a properly designed data collecting form.

In the same year the overall rate of early neonatal death (i.e. death within seven days of delivery) was 0.375% in Italy and 0.319% in our Region. Some of the above-mentioned drawbacks apply also to these data; for instance, most neonatal deaths due to respiratory distress might more likely be attributed to prematurity, which is not considered as a separate cause, rather than to truly isolated respiratory distress.

In Italy, the maternal mortality rate in 1994 was 3.54 per 100,000 births.

More significant is the analysis of the trends in the rates of stillbirths, perinatal death (stillbirth plus early neonatal death) and maternal mortality in Italy from 1960 to 1994 (see Figs. 1 and 2 below).
In conclusion, most of the problems encountered in the collection and analysis of perinatal care data seem to originate in the lack of specific data in the data collecting sheets and the electronic database. We believe that the creation of an international database could play a major role in defining the areas of critical interest. This would also be very important for the identification of those centres where standards are at their highest; thus partnerships and the reciprocal exchange of knowledge and experience could be established. Last but not least, this would be another step towards the optimal use of our resources and a reduction in costs.

The Portuguese experience
Dr Humberto Krohn

The Portuguese health system is based on three levels of medical care. The first level is held by the “family doctor”, a generalist who looks after the everyday problems of his patients, the second level is made up of regional hospitals with limited possibilities of diagnosis and treatment, finally, the third level structure are the central hospitals, where all the patients coming from level one and two are sent if their diagnosis or treatment need more sophisticated procedures. All of them with emergency services, organized in the same way.

The Maternity of Julio Dinis, in Oporto, is a third level facility. Due to some problems with the lower level structures, too many pregnant women are sent there who have no real need for specialized follow-up.
In order to correct the overcrowding of consultation facilities, some programmes of cooperation with the level one structures were implemented.

The protocols of such cooperative efforts were presented, such as the results of this innovative programme in Portugal.

**The Polish experience**

**Dr Marta Szymankiewicz**

The collection of perinatal data was started in 1948 by the Institute of Mother and Child (IMC). Once a year, each hospital sends reports on MZ-29 forms to the IMC. The data are collected by regional offices of Mother and Child Health and aggregated and published by the IMC. The data reflect hospital statistics and the level of health care in the place of hospitalization.

The National Centre for Statistics’ Department of Health collects perinatal data based on birth and death certificates. These data reflect the level of health care according to the place where a patient lives. According to these statistics (Table 2), the infant mortality rate decreased by 2 promiles (900 survivals in the country) between 1996–1997 and by more than 7 promiles in the last 5 years (10.2 promiles in 1997).

The National Program of Improvement in Perinatal Care began in 1993. Its main goal is to monitor the quality of perinatal care throughout the country. On the tenth day of each month, each department sends data to the regional office. Once per year, the data are aggregated and published. Approximately 40% of centres across the country submit accurate data regarding treatments, procedures, and transport of the newborn.

<table>
<thead>
<tr>
<th>Year</th>
<th>No. of deliveries</th>
<th>500–999 grams</th>
<th>Perinatal mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td>1989</td>
<td>550127</td>
<td>4460</td>
<td>890.4</td>
</tr>
<tr>
<td>1990</td>
<td>543689</td>
<td>4655</td>
<td>857.8</td>
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<tr>
<td>1991</td>
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<td>482591</td>
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<td>464177</td>
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<tr>
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<td>435816</td>
<td>2722</td>
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</tr>
<tr>
<td>1996</td>
<td>423470</td>
<td>2420</td>
<td>722.3</td>
</tr>
</tbody>
</table>

Table 2. Perinatal mortality according to birth weight
Table 3. Perinatal mortality stratified by city

<table>
<thead>
<tr>
<th>Deliveries &lt; 500g</th>
<th>No.</th>
<th>Stillbirths</th>
<th>Deaths</th>
<th>Stillbirths and deaths</th>
<th>PM</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
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<td>Szczecinskie</td>
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<td>6.9</td>
<td>157</td>
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<tr>
<td>Bydgoskie</td>
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<td>3.1</td>
<td>82</td>
<td>6.3</td>
<td>101</td>
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<tr>
<td>Elblaskie</td>
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<tr>
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<td>8.1</td>
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</tr>
<tr>
<td>Lubelskie</td>
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<td>5.3</td>
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<td>7.4</td>
<td>41</td>
</tr>
<tr>
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<td>2849</td>
<td>6.7</td>
<td>2402</td>
</tr>
</tbody>
</table>

Perinatal Care Reorganization Programme in Lithuania
Dr Jurate Buinauskiene

- 1990: Perinatal Board was organized at the Ministry of Health.
- 1991: WHO recommendations for registering newborns with birth weights of 500 grams or after 22 weeks gestation were introduced.
- 1992–1996: Perinatal Care Reorganization Programme was put in place and created a three-tiered medial care system that regionalized data collection and analysis:
  - Level I: outpatient departments at maternity centres and obstetrical departments in district hospitals (total number of units = 47).
  - Level II: outpatient clinics, obstetric departments and neonatal units of regional hospitals and some of the obstetrical clinics in Vilnius and Kaunas (total number of units = 6).
  - Level III: perinatal centres at Vilnius University Women’s and Neonatal Clinics and the Kaunas Medical University Hospital Obstetrical and Neonatal Clinics (total number of units = 2).

See below diagram of flow of data in the data collection process.
The neonatal, early neonatal, perinatal, and maternal mortality rates in Lithuania and the Kaunas Perinatal Centre have all greatly decreased since the introduction of the Perinatal Reorganization Programme.
Early neonatal (0–6 days) mortality rate in Lithuania per 1000 live births

Neonatal (0–27 days) mortality in Lithuania per 1000 live births
The second stage of the Perinatal Care Reorganization Programme is planned for 1997–2000.

**Experiences from the Palestinian Authority**

**Dr Izzeldin Abuelaish**

The health sector of the West Bank and the Gaza Strip was controlled in the past by the Israeli civil administration. Health services continued to be provided by four major providers: namely the Ministry of Health of the Palestinian Authority, UNRWA, nongovernmental organizations (NGOs) and the private sector. The overall health situation remained poor by international standards since the Palestinian assumption of responsibility for health in the Gaza Strip and Jericho. This is because of fragmentation, maldistribution of health services and imbalance between the basic needs of the rapidly growing population and the poor infrastructure which suffered several years of neglect during Israeli occupation. The total number of hospital beds in the Gaza Strip is about 1000, and the bed/person ratio is one per 1100. Also, the workload at the general clinics continues to be high with an average number of 100–120 consultations per doctor per day.

The Gaza Strip is situated along the Mediterranean Sea, with a square area of 370 km. The population of the Gaza Strip in 1994 was 807,921 excluding the returnees from abroad after the peace process. In 1998 the estimated population is around 200,000. The Gaza strip has a high population density of 2150 persons per sq. km. Contrary to the situation in the West Bank, the majority of the Gazian people are refugees living in 8 refugee camps (3/4 of the population are refugees. Fifty percent of the total population are under 15 years old, thus 50% of the population is dependent on the other half. The economic situation and therefore the welfare of workers and their families have continued to be influenced by the prevailing political climate. Only 30–40% of the population have health insurance.

Statistics on maternal and infant mortality are incomplete and unreliable due to underreporting of deaths, with women of reproductive age and children below the age of 15 years comprising two thirds of the registered Palestinian refugee population.
The maternal mortality rate of approximately 30–40 per hundred thousand live births is due primarily to toxaemia of pregnancy, pulmonary embolism and haemorrhage mainly postpartum haemorrhage. Most maternal mortalities are avoidable. 60% of the pregnant women are high risk. The main risk factors are multiparity and anaemia. It was found that 32.8% of pregnant women at first contact with antenatal service are anaemic, and increased to 44% in third trimester.

Also, 85% of children are anaemic. According to the best estimates infant mortality rate is approximately 40 per 1000 live births. High proportion of deaths during the neonatal period (first month of life), representing 52% of all reported deaths.

The main causes of infant mortality are:

1. prematurity
2. congenital malformations
3. respiratory infections
4. gastroenteritis.

These causes are attributed to the poor social, economic and housing situation of the Palestinian people. The average family consists of seven persons living in one room, or at best two rooms.

Conclusion

Health is intimately related to human rights, to peace and to development. Disease knows no barriers. Peace and the respect of human rights must be the basic foundations of any health care system.

A comprehensive approach to perinatal care in Europe – the Israeli example at the Rabin Medical Center

<table>
<thead>
<tr>
<th>Maternal mortality</th>
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<tr>
<td>Dr Israel Yoles</td>
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</table>

Maternal mortality rates are collected by the Israeli Centre on Maternal Mortality. These rates have declined over the past few decades. Previously, women in older age groups died mainly of pulmonary embolisms. Younger women died of complications of multiple pregnancies or emergency Caesarean sections.

The maternal mortality rates have declined for a number of reasons. First, prenatal care was made freely available and now women average 8 out of 10 visits. Second, all hospitals are university affiliated and the staff is highly trained and motivated. Thirdly, problems or complications are routinely aggressively treated. Lastly, the general health of women in the country has been steadily increasing.

<table>
<thead>
<tr>
<th>Outcomes of low birth weight babies (&lt;1500 g)</th>
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<tr>
<td>Dr Brian Reichman</td>
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</table>

All around the world, the survival rate among very low birth weight babies (VLBW) has been increasing. This has placed an increased demand on neonatal intensive care units. In 1994, the
Israeli Perinatal Society decided that it was time to start collecting data on all low birth weight babies. A system was set up in the Israeli Ministry of Health to do that. The data processing system involves data collection, evaluation, and validation. A report is then sent to the head of each department. Mandatory hospital re-assessment of each LBW child is performed when the child is two years of age and information on two-year survival rates is maintained.

1995 was the first year of data collection activities. There were 1286 LBW babies delivered that year. Data were obtained on 95% of them. Some of the data given are provided below:

- *Maternal characteristics*: 25% underwent infertility treatment, 50% received *in vitro* fertilization (IVF), and 60% had Caesarean sections.
- *Commonly used treatments*: high frequency ventilation, oxygen, home oxygen, PDA surgery, cryotherapy, VP shunt placement, surgery for necrotizing enterocolitis (NEC).

**Discussion points:**

Q: How long do neonates remain in the department when their weight is under 1000 grams and what is the cost of caring for such a child?

A: For infants under 1500 grams, the average stay is 55 days but, of course, the inter-hospital variability is quite large. For infants under 1000 grams, the average hospital stay is 85–90 days. Unfortunately, we have no estimate of the costs of caring for these children in Israel because of the structure of our reimbursement system. Under this system, hospitals get US $15 000 for every four days of NICU stay.

Q: How do you follow up with babies under 1500 g after discharge?

A: There is no follow-up at the hospital level. The babies go to paediatricians out in the community.

Q: What is the survival rate for these babies after discharge?

A: After discharge, approximately 10% die.

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**The critically ill obstetric patient**

*Dr Pierre Singer*

Obstetrical patients tend to be young and healthy prior to pregnancy. Thus, when they have complications, they present special problems that require special skills. Obstetricians, in general, are accustomed to caring for healthy women and are therefore not qualified to handle very complicated cases. These women need ICU specialists.

In a retrospective study conducted from January 1994 – February 1997, 850 patients were studied. The study looked at the demographic profile of patients admitted to ICU’s, their diagnoses at admission, illness severity scores, and reviewed the rational for admission. A brief summary of this data is provided below:

- **Demography**: median age was 30 years; median gestational age at admission was 32 weeks; median ICU stay was 25 hours.
- **Severity scores:** Apache II severity scores were used. They rely on physiological not anatomical parameters. Average score in the study was 26 which is very low. There was a 98% survival rate (only one patient died).

- **Therapeutic score (TISS):** among TISS scores, 20 is an average score. Most patients had scores greater than 20; five patients had scores less than 20; four had very high scores.

- **Main diagnoses:** 82% were admitted after Caesarean section. Main reasons for admission were pre-eclampsia, high blood pressure, haemorrhage, and placenta previa. Fourteen patients had pulmonary oedema due to sepsis with concomitant fluid overload, myocardial infarction, and haemorrhage. Two patients were admitted secondary to complications of anaesthesia. Other diagnoses include severe bleeding, high Apache score, and coagulation disorders.

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**Extreme prematurity – The Schneider Children’s Medical Centre**  
**Dr Amir Kimia**

The Schneider Children’s Medical Centre specializes in the care of premature newborns and neonates with multiple medical problems. It is a 40 bed department but is usually overcrowded with more than fifty babies. For the last half of 1997, there were 550 admissions of which 35 were due to multiple pregnancies. A brief description of patient characteristics was presented including:

- Estimated age distribution: average age is 30–34 weeks; many infants are transported in with multiple anomalies especially cardiac anomalies;
- Weight distributions
- Neonatal morbidities: intraventricular haemorrhage is the major problem
- In vitro fertilization (IVF) rates: which are one the rise
- Bronchopulmonary dysplasia (BPD) rate analysis
- Incidence of necrotizing enterocolitis (NEC)
- Incidence of disseminated intravascular coagulation (DIC): remains a major problem with the main cause being sepsis
- Incidence of rupture of placenta (ROP).

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**Transport in utero: Medical Centre, Eilat to Rabin Medical Center**  
**Dr Avinoam Tzabari**

The Medical Centre in Eilat is a small community hospital which serves a population of 47,000. It is a delivery centre isolated from a NICU. Until two years ago, there were no guidelines for handling emergency situations which required maternal and/or neonatal transport. Mothers were usually sent to the hospital of their attending physician. Now there is an established transport system with the Rabin Medical Center and the Schneider’s Children’s Medical Centre, both in Petach Tikva. The Rabin Medical Center has an emergency hotline that is available 24 hours per day. With this hotline, we can communicate the details and status of each emergency. What follows is a brief description of our transport system:
• Modes of transport:
  - **Ambulance:** travel time is 4 1/2 hours plus 15 minutes ordering time; cost US $400.
  - **Commercial airline:** 1 hour travel time; available 6 a.m. to 10 p.m.; cost US $350.
  - **Army helicopter:** 2 hour transport time; good when mother must be transported supine as in cases of eclampsia, pre-eclampsia or toxaemia; cost US $1200.
  - 23 cases were transported over a 16 month period; most by air (56.5% by commercial airline, 39.2% by helicopter).

• Maternal demographic data were presented.

• Obstetric complications requiring maternal transport was presented.

• Gestational age of maternal transports was presented.

• Neonatal outcomes:
  - 100% of infants from these 23 cases were alive after delivery.
  - 20/23 cases died after delivery.

• Neonatal mortality was presented: three main causes of death included RDS and sepsis.

**Discussion points:**

Q: Why do you use helicopters given their extreme costs?
A: Because the transport time with a helicopter is only 2 hours whereas transport with an ambulance is 4 1/2 hours. Besides, you can keep the woman in the delivery room under strict medical supervision until helicopter arrives. Also, there is no mobile NICU in Israel. The helicopters are from the army and the bill is rarely paid so the price is not really valid. On the other hand, when you look at the price for using a commercial airline, it only shows the cost of the actual flight, but not the costs of the medical team.

Q: What kind of transport medical team goes with the transport to support the patient?
A: It depends on the case and the complications. If there is the risk of eminent delivery, then a team of neonatologists and obstetricians from Beilinson comes. If there are no risks, they travel with a midwife from the hospital of origin.

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**The Macrosomic offspring**

**Dr Moshe Hod**

What are the main two problems when dealing with a macrosomic baby? The immediate problem is deciding how to handle what will likely be a traumatic delivery (e.g. shoulder dystocia). The long term problem is how to manage the fetal origins of adult disease (described below).

(a) **Traumatic delivery**

The effectiveness and costs of elective Caesarean delivery for fetal macrosomia diagnosed by ultrasound was discussed. In addition, the rationale for early delivery of cases of gestational diabetes was discussed.

Data on a study conducted at the Rabin Medical Center on outcomes in diabetic pregnancies versus control pregnancies were presented. In 1995, a protocol was established in which the
mode of delivery is decided at 38 weeks based on ultrasound estimated fetal weight, thus reducing the rate of traumatic delivery.

(b) *Fetal origin of adult disease*

Recently, data have been published supporting an emerging theory that many adult diseases can be linked to fetal or perinatal events. The hypothesis is that there are metabolic adaptations *in utero* which can have lifelong consequences. For example, fetal under-nutrition or being the adult offspring of a diabetic mother seems to increase one’s risk of developing certain diseases later on in adult life (e.g. syndrome-X).

**Presentation of twinning projects**

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<th>Introduction</th>
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<td>Dr Petr Velebil</td>
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Briefly reported on the twinning project between the Czech Republic and a country referred to as Country X. This twinning project was presented as an example of how collaborations can be achieved based on data comparisons between sites. These two countries decided to pair up because they had comparable populations and information systems in place. The main objectives were to exchange data and identify areas with the greatest potential for improvement.

Both countries have similar birth rates per 1000 population. They have similar trends in decreasing early neonatal mortality but much higher rates of and an increasing trend in late neonatal and post-neonatal mortality rates. Thus, late neonatal and post-neonatal mortality were identified as the two components of infant mortality with the greatest potential for improvement.

When stillbirth rates were compared, it was found that there is a higher contribution of stillbirths among normal birth weight babies in Country X. Thus, addressing this problem became the second priority. Similarly, there is a higher early neonatal mortality rate among normal birth weight babies in Country X so addressing this problem became the third priority.

Analysis of selected perinatal indicators revealed that Country X has a higher intrapartum death rate, a higher proportion of women who receive no prenatal care, a higher proportion of unattended births, and a slightly higher Caesarean section rate. Thus, it was concluded that there is a need to lower the current CS rate and improve late prenatal and intrapartum care in Country X. This became the fourth and final priority.

Based on the Czech experience with this twinning partnership, Dr Velebil proposed a model for establishing twinning projects. This model is based on an exchange of people (on-site visits) and data (i.e. comparative analysis). After such exchanges have occurred, collaborating centres should determine the quality of existing information systems, set priorities, plan interventions, strategize for evaluative efforts, and assess the cost-effectiveness of proposed interventions.

**The United Kingdom/Kyrgyzstan Project**

Dr E. Vikhlyaeva, Dr G. Asymbekova, Dr P. Banfield

The goal of the project was to evaluate the use of OBSQID data collection tools for improving perinatal outcomes. Participating twinning centres were located in Wales (United Kingdom); Moscow (Russia Federation); and Kyrgyzstan.
Initially, analysis of perinatal outcomes in each country was performed. Regional characteristics of each participating centre based on 1997 data were identified. The delivery rates, however, were very similar for all three countries.

A training workshop for discussing OBSQID BIS and perinatal audit programmes was arranged. Arrangements were also made to collect data on all births in each participating centre for a one month period during 1998. On the basis of these results, intervention programs were designed for each centre.

A series of training seminars were organized. An initial seminar for potential participants was held in Moscow on 23–26 June 1998. The goal was to establish common terminology for data collection. A second training seminar on perinatology was held in Bishkek on 12–16 October 1998. A third seminar on neonatal intensive care is planned for December 1998 in Bishkek.

Some of the priorities established for future activities are:

- First presentation of results and discussion of future activities is planned for January 1999.
- Priority for the second stage of the pilot study is the installation of the BIS in each centre to be used for the whole of 1999.
- Monthly PAD data analysis will be done in the Moscow Coordinating Centre with subsequent presentation of results to WHO/EURO.

### Triplet Project: The Romanian, Poland, and Ukraine twinning project

**Dr K. Kornacka**

The main sponsors of this project are the Children’s Medical Care Foundation in Los Angeles, California and the University School of Medical Sciences in Poznan, Poland.

**Why Poland and the Ukraine?**

The main reasons are because there is a relatively short distance between the two countries, there is reliable public transport between the collaborating centres, the histories of these countries (post-communist) is very similar as are the languages.

**The project**

The project began with two Ukrainian doctors – Dr Olga Detsyk (Head, Lviv Regional Neonatal Centre) and Dr Dmytro Dobriansky (Faculty and Hospital of Paediatrics) – visiting Poland for three months. They observed in the NICU and were trained in intensive care medicine.

Dr Kornacka then visited two neonatal units in Lviv. Lviv is a city with 40 neonatal departments, a total of 70 neonatologists, and handled 28 000 deliveries in 1997. Their resources are limited. There is an insufficient number of incubators, only 2 ventilators, one pulse oximeter, no oxygen analysers, one blood pressure monitor, no infusion pump, glucose only for parenteral nutrition, and no surfactant. The neonatal department of the Medical Academy, however, has a good rooming-in department, and a high percent of mothers who breast feed. Unfortunately, their intensive care unit facilities are sub-optimal.
Results

As a result of the collaborative project, 14 neonatologists were trained in resuscitation of the newborn, neonatal transport, introduced to a three level perinatal care system, and trained in NICU management.

Future goals

These include establishing research projects for collecting epidemiological data, developing new therapies, and initiating basic science research. They hope to introduce new treatments and technologies (e.g. NO, HFIV, and SMIV) in each country. Collaboration with the Bucharest State Hospital began two months ago. A report on this collaboration will be presented at the Sixth Workshop.

The Georgia/Israel twinning project
Dr M. Hod, Dr N. Asatiani

The collaboration started in 1994. They wanted to find a way to obtain rapid results in diabetes research. It was decided that research during pregnancy would be most effective since there is a nine-month incubation period and a continuous supply of patients. The main project activities include the establishment of postgraduate training courses and the visit to Israel and training of two Georgian doctors (including Dr Asatiani). These doctors returned to Georgia and established the Diabetes in Pregnancy Centre. Dr Asatiani presented data from this centre which will be published in a journal article soon.

Of note, up until the founding of the Diabetes in Pregnancy Centre, Georgian women with diabetes were not allowed to conceive. Since the centre was founded, these women have been allowed to conceive and are followed intensively. Thirty-two women with IDDM have delivered normal babies.

Thursday working groups: experiences with pan-European case-based and perinatal aggregated data

WG 1: Experiences using the PAD, BIS, and other data collection tools
Moderators: Professor Karel Marsál, Dr Charles Savona-Ventura

Goals

- Examine experiences of countries that use standardized data collection forms to record case-based and/or aggregated perinatal data.
- Review data items on forms and discuss how to incorporate OBSQID variables and indicators into national data sheets.
- Discuss ways to introduce OBSQID tools in countries where no such data tools exist.
- Discuss how data can be aggregated at data nodes (local, regional, national).
- Discuss obstacles encountered when introducing data collection systems to personnel at the local level and strategies for overcoming them.
Discussion Points:

- The results of the EAPM questionnaire were presented. The questionnaire was designed to gather information on the types of data items collected on national data forms in EAPM member countries. Eighteen of the 22 EAPM member countries submitted forms and 14 items were found to be present on the majority of forms. The EAPM decided that the present birth and perinatal death certificates used for civic purposes are not useful for collecting perinatal quality indicators thus, the EAPM should collaborate with the OBGGID Project and the FIGO which are both addressing similar issues.

- It was agreed that the BIS is, in general very useful and easy to use. However, it is not always user friendly particularly if data collectors have not been formally trained how to use the form. Such training will help to improve the quality of the data collected.

- The BIS includes too many items which are not meaningful to local and national clinicians and bodies.

- Many additional (peripheral) items have been added to the original set of indicators. Most of these new items are difficult to collect.

- The validity and feasibility of many items are questionable (e.g. violence, time to hospital).

- The lack of definitions of the items on the PAD is problematic.

- Some of the BIS items are not on routine patient files. It is recommended that the design of the form follow clinical practices more closely.

- Recommendation that all countries move towards electronic patient files.

- PAD shows differences in outcomes but does not provide any information about why these differences exist. The BIS tries to explain these differences.

Recommendations:

1. Present PAD and BIS need revision.

2. PAD definitions should be made available.

3. Feasibility and validity of the data collected must be continually controlled at the local and regional levels.

4. Staff collecting data should be aware of the definitions of the items and trained how to properly use the forms for data collection.

5. The case-based data form should primarily contain data items which are routinely collected in clinical practice.

Comments:

- When making revisions, we should be careful not to extend the total number of items too much. We should start by identifying what is not necessary and then make revisions or additions.

- Suggest that the WG state which items they think are important to keep and which should go.

- Recommend that rather than make revisions again, a small group represented by the WHO, EAPM, and FIGO be formed to decide which items to keep.

- Revisions will likely happen every year but will be minor.
- OBSQID BIS users should provide regular feedback to guide future revisions.
- With a multicountry data collection form, there will never be a “final product”. Changes will be made on a regular basis.

**WG 2: Using QCT databases for continuous quality and technology assessment**

*Moderators: Dr Martin Ditte, Dr Tom Weber*

**Goals:**
- Focus on ways case-based and aggregated data can be used to generate epidemiological data at local, regional, or national levels; identify best practices; and highlight specific areas in need of quality improvement.
- Discuss how to design national server networks which integrate data vertically from the local to regional to national levels while producing data which are internationally comparable.
- Point out ways data can be used in an international context to successfully compete for needed financial and/or technological assistance.

**Discussion points:**
- Common definitions and language must be used universally.
- Need for vertical transfers and processing of data forms.
- Identify who does/will perform data analysis.
- Data collection forms.
- How to check the quality of data regularly.
- Confidentiality issues.
- Lengthy turn-around time from data collection to presentation of results in some countries makes it impossible for the data to have an impact clinical practices.
- How to compare maternal and late neonatal mortality.

**Recommendations:**
1. Countries should identify one person to review data sheets to ensure their reliability.
2. Countries should identify one person to train other data collectors in proper techniques.
3. Data analysis should be done by clinicians, not people unfamiliar with the profession.
4. We must consider the legal issues surrounding the availability and distribution of data and data audits, and how they can potentially compromise confidentiality and patient rights.
5. Decrease the turn-around time for presenting the results of data analysis.
6. Find a reliable way to compare maternal and late neonatal mortality.
WG 3: Designing and integrating perinatal quality of care development (QCD) programmes into national QCD policies

Moderators: Dr Boas Lev, Dr Arnon Samueloff

Goals:
Participants discussed their potential role in drafting, introducing and implementing a perinatal component within national QCD policies.

Discussion points:
- Professional excellence: discussed how quality evaluations should be performed.
- Medical/legal issues surrounding quality databases.
- Efficiency in use of medical resources including:
  - Screening tests for CMV or HIV viral infections
  - National preventive programs and health screening programmes
  - Multicentre trials can provide information about differences in the quality of health services and help identify best clinical practices and inform clinical practice guideline development.

Recommendations:
1. Professional excellence:
   - Recommend performing both internal (department or hospital based) and external quality evaluations.
   - Internal evaluation can be done quickly allowing immediate actions to be taken should the need arise.
   - External evaluations should be done by a body from outside the profession (e.g. governmental body) which would perhaps be more objective than those conducted from within the profession.
   - In larger countries, evaluations should be done at the national, regional, and local (hospital or clinic) levels.
   - Clinical guidelines be established and published to regulate compliance.
2. Medical legal issues surrounding quality databases: need models from countries with more experience in this area (e.g. the United Kingdom).
3. Efficiency of use of medical resources:
   - Recommendations for national preventive and screening programs should be made.
   - Recommend conducting multicentre trials to obtain information on how to best obtain quality assurance.
4. Consider recommendations made at the European Forum of Medical Associations, Utrecht, 28–29 January 1993:
   - Promote the professional responsibility for QCD and institute internal self-evaluative mechanisms within national medical associations.
Promote the development of strategic quality markers by individual medical specialities which includes consideration of the personal experience of patients.

Institute external quality initiatives including mechanisms for the support, supervision, and establishment of protected comparative databases retrieved from appropriate recording of patient care data and managed by the profession to ensure that confidentiality for both patient and physicians is guaranteed.

Disseminate information on best-demonstrated practices and promote their constructive application in other clinical sites.

Promote the description of good practices via consensus conferences and other methods that produce statements on medical care that can be used as a reference in evaluative mechanisms.

Acknowledge that, apart from the fact that research is the basis for QCD, there is a need for research on QCD itself.

WG 4: Legal issues and confidentiality

Moderators: Dr Dan Peleg, Dr Kirsten Staehr Johansen

Goals:
- Discuss confidentiality and respect for the legal and ethical rights of patients.
- Review how these issues have been dealt with in some member states with a view to bringing successful legislation and experience gained to the forefront.

Discussion Points:
- Importance of databases:
  - Can help demonstrate that you are not worse than others.
  - Can identify centres (or countries) with the best outcomes in a particular health area.
  - Can identify centres in the best compliance with national standards of care.
- Legal issues:
  - Number of lawsuits brought by patients or their families against doctors is not as high in Europe as in the United States but it is getting worse.
  - Courts may request that physicians provide their professional results at trials.
  - Physicians may not have to testify if the testimony will reveal details of another individual’s case.

Recommendations:
1. Countries need to consider legal implications of clinical databases when putting together national QCD programmes.
2. The experiences of countries with a history of dealing with the legal aspects of patient data should be provided for the benefit of those who are just beginning to encounter these problems.
Friday Working Groups: case-based data in obstetric specialties

WG 1: Diabetes in pregnancy

Moderators: Dr Moshe Hod, Dr Hasan Ilkova, Dr Gyula Tamas, Dr Jan Wilczynski

Goals:
- Discuss Dr G. Tamas’ Basic Information Sheet (BIS) for Diabetes and Pregnancy.
- Make recommendations for improving the Diabetes BIS.
- Discuss how this BIS can be incorporated into OBSQID data collection activities and into the OBSQID database.

Discussion points:
- Dr G. Tamas presented his Basic Information Sheet (BIS) for Diabetes and Pregnancy.
- The BIS was accepted for use as an OBSQID data collection tool to be used by WHO member states in its current form for submitting data to the OBSQID database.
- The BIS will be reviewed and modified next year if necessary.
- Data collection activities should start immediately:
  - The databases are located in Hungary (Dr G. Tamas, Diabetes Database) and in Israel (Dr M. Hod, Obstetrics Database).
  - Whoever wants to start collecting data may do so. Data should be collected both retrospectively for 1998 and prospectively starting immediately. All data should be submitted by March, 1999 so it can be analysed.
  - Data will also be sent to WHO/QCT for objective, external analysis and confirmation.
  - Presentation of the results will be made at the 10th Anniversary of the St Vincent Declaration meeting to be held 10–12 October, 1999.

*See Annex H for a copy of the draft Basic Information Sheet for Diabetes and Pregnancy.

WG 2: Multiple pregnancy

Moderators: Dr Louis Keith, Professor Alexander Schoenfeld

Goals:
- Consider how the issue of multiple pregnancy relates to the OBSQID project.
- Make recommendations for developing a separate OBSQID BIS on this topic.

Discussion points:
- Made suggestions of items related to multiple pregnancy to add to the OBSQID BIS.
Dr Keith presented a document containing suggestions for creating a database for multiple pregnancies based, in part, on The Program for an International Database of Multiple Births (IDBMB) held on 10 February 1995. The suggestions were as follows:

- **Mode of conception**
  Currently, information about the mode of conception is hospital-based. Thus, the population-based figures needed to establish denominators for outcome studies are missing. In addition, the relationship between outcomes and different modes of conception is still unknown. We must collect data on whether conception was spontaneous, ovulation induction, IVF, or via ICSI.

- **Embryonic/fetal demise**
  There is an increasing interest in the association between fetal demise and malformations or cerebral palsy in the survivor. Thus, it is important to know if a given pregnancy (multiple or singleton) is associated with a vanishing twin, embryo reduction, or fetal death.

- **Familial twinning**
  Twins, mainly DZ, have a strong familial tendency. It is unknown if the trait of “having a twin in the family” is an advantage or disadvantage for a given twin pregnancy. The database should contain information on whether there is a history of spontaneous twins in the family and if they are recurrent, paternal or maternal.

- **Placental inspection**
  Because of the numerous differences between MZ and DZ twins, establishing chorionicity and amnionicity is probably the most important issue in multiple pregnancy research. The database should contain data about the placenta such as how many there were and the type (DC-separate, DC-fused).

- **ART related questions**
  If ART was used in a pregnancy, it is important to record the number of embryo transfers (ETs) in order to establish the true zygotic splitting rate. It is also important to know the embryos/fetus ratio.

- **Other potential topics to be investigated:**
  - Fetal and neonatal mortality rates
  - Birth weight distributions among multiples
  - MZ/DZ proportions according to Weinberg’s rule
  - Sex proportions in twins and triplets

- **We pondered the question:** what would be the advantage of establishing a database on multiple pregnancies. Answer: we will not only have a pan-European database, but will gain data which are not currently maintained in other databases. For example, the U.S. birth certificates do not record mode of conception or whether an infant was part of a multiple pregnancy.

- **Additional suggestions were made which do not necessarily relate just to OBSQID:**
  - We need to publish the fact that ALL multiple pregnancies are high risk pregnancies. This is particularly important in light of recent events such as older women (age >50) undergoing IVF, and ETs leading to multiple pregnancies involving 6+ births.

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2 Participating organizations included: Multiple Births Foundation, London; Center for the Study of Multiple Births, Chicago; Triplet Connection, USA; Association for the Scientific study of Multiple Births, Belgium; Working Party on Multiple Births, International Society for the Study of Twins, Rome; ABC Club, Germany; Twin Services, California; National Center for Health statistics, USA.
Multiple pregnancies need early screening (ultrasound, choriocentesis) to assess the presence of other risks such as vanishing twin syndrome, and fetal malformations. It should also be emphasized that early screening in all pregnancies allows for the early identification of multiple pregnancies and therefore permits early interventions and management.

We should attempt to discover the reasons for discordant growth among multiples and what can be done about it. Of course, early ultrasound screening would help.

We should examine the effects of fetal demise of the surviving fetus(es) both before and after 26 weeks gestation.

As a profession, we need to avoid higher order multiple pregnancies. One way to do so is to encourage limitations on the number of fetal transfers during IVF.

**WG 3: Neonatal care**

*Moderators: Professor Arthur Eidelman, Dr Jan Mazela*

**Goals:** Present and discuss the new Neonatal BIS.

**Discussion points:**

- The first sample Neonatal BIS was developed this year as a collaborative effort between the Department of Neonatology, Karol Marcinkowski University of Medical Sciences in Poznan, Poland and the QCT/WHO office. It was piloted during the last few weeks Poland.
- Reasons for developing the form:
  - Neonatal section on the OBSQID form is inadequate for data collection on infants who require additional care.
- Dr Jan Mazela presented the results of the pilot of the Neonatal BIS and the form was discussed.

**Recommendations:**

1. A case-based form be developed which combines obstetrical and neonatal data items.
2. OBSQID BIS be divided into two parts:
   - section for healthy newborns receiving routine care, and
   - a section for sick newborns requiring additional care.
3. Additions to the OBSQID BIS:
   - intrapartum antibiotics
   - antepartum steroids
   - length of PROM
   - FHR (normal or abnormal)
4. Delete from the Neonatal BIS:
   - length of baby
   - Apgar at 10 min
   - first hour of life gases
   - cord arterial pH
5. Additions to the Neonatal BIS:
   - screening items (done/not done)
   - prevention items (done/not done)
   - nutrition
   - HCT
   - glucose and dextrose

6. Sick newborn form which includes:
   - CRIB score
   - respiratory care (i.e. length in days)
   - drugs such as steroids (single dose, 48+ hours), diuretics, anticoagulants
   - screening of premature infants (hearing exam, eye exam, head)
   - discharge (date, medications, neuro-developmental exam)

7. Problems to solve:
   - How to record transfer when an infant returns to a 2nd level hospital from 3rd level centre.
   - What to do about countries that do not use ICD codes.

WG 4: Hypertension in pregnancy

Moderators: Dr Jacob Bar, Dr Grzegorz Breborowicz

**Goals:** Discuss development of a hypertension in pregnancy BIS.

**Discussion points:**

- Hypertension BIS should be a continuation of the original OBSQID BIS thus we only discussed things not already on OBSQID BIS.
- We tried to agree on a definition of hypertension but quickly stopped because it became obvious it is too complicated.

**Recommendations:**

Hypertension BIS sheet should contain:

1. Reproductive history of woman and her family members including: PIH, pre-eclampsia, eclampsia, and hypertension treatment prior to current pregnancy.

2. Current pregnancy history:
   - Blood pressure: highest, values during pregnancy (at admission, first recorded, 24h ABPM), and hospital admissions before pregnancy
   - Proteinuria: onset, dipstick, and two hour collection
   - Laboratory tests: hct, ptsls, glucose, coags, liver profile, and uric acid
   - Treatment: anti-hypertensives, onset of treatment, duration of treatment, intrapartum and postpartum treatment; steroids, or other medications/treatments

3. Birth: emergency CS for specific indications such as severe maternal hypertension or fetal distress.
WG 5: Blood transfusion
Moderators: Dr Cristina Russu, Dr Dina Pfeifer

Goals: Discuss development of a blood transfusion BIS.

Discussion points:
- The debate: to transfuse or not.
- OBSQID BIS does not adequately record blood use but a separate BIS is not needed.
- Blood use practices.
- Knowledge of practitioners about blood use and misuse.
- Antenatal reporting of maternal co-morbidities, iron supplementation, lab values.
- Maternal deaths: assess the role of haemorrhage as a cause of maternal death.
- Hazards of blood transfusions: haemolytic reactions, chill fever reactions, contaminated blood, infections.
- Reasons for reduced use of blood transfusion including fears of both patients and doctors about risks, professional realization that transfusions are unnecessary in many cases, issues of cost.

Recommendations:
1. Do not recommend creating a separate BIS for blood issues. Rather we recommend adding blood items to the current BIS.
2. Establish blood utilization team within OBSQID project to:
   - study blood usage practices
   - study side effects of blood components
   - offer training on proper blood management to staff
   - analyse data on blood use and produce reports
   - formulate guidelines on blood use.
3. Include education/training programs on blood use in university and postgraduate curricula.
4. Improve antenatal data.
   - improve recording of maternal history of blood conditions such as haemophilia, von Willebrands disease, and ITP.
   - record maternal use of iron supplementation (e.g. when medication started).
   - improve recording of lab tests such as TIBC, UIBC, ferritin, free Fe, and coagulograms.
5. Improve blood use practices such as in operative techniques, patient supervision, and the use of alternative measures (autologous transfusions, acute hemodilution prior to CS, and step wise uterine devascularization).

* Ms Dina Pfeifer gave a presentation on the blood use and misuse.
WG 6: Ultrasonography
Moderator: Dr Cihat Sen

Goals: Discuss development of a ultrasonography BIS

Discussion points:

- The effects of ultrasound on perinatal mortality and morbidity:
  - Ultrasound useful for detecting fetal malformations.
  - Misdiagnosis is very important reality.
  - Ultrasonographers should be trained in fetal scanning.
- Scanning for fetal malformation and maturity:
  - Rationale for scan depend on whether termination is possible or not.
  - If termination is possible, the malformation should be confirmed by autopsy if necessary.
- Scanning near to term should be available for delivery.
- The cranial ultrasound for neonates should be performed where clinically indicated.

Recommendations:

* These recommendations will be discussed in more detail at the Sixth Workshop.
1. 10–14 weeks scan for detecting early fetal anomalies and nuchal translucency.
2. 20–22 weeks scan for fetal malformations and assessment of fetal growth.
3. 32 weeks scan for fetal growth.
4. Scan near to term for delivery (fetal weight, position, etc)

Summary of the Workshop

The participants of the Fifth Workshop critically examined the accomplishments of the first five years of the OBSQID project and shared their experiences and ideas related to the development of quality of care technologies and practices in the field of perinatal medicine. Participants also examined both WHO and country specific models for data collection and management and discussed their merits and weaknesses. A number of participants reported on their practical experiences using the OBSQID BIS and made suggestions for further improving the form. An important topic discussed was how countries can develop national QCD policies based on existing perinatal QCD programmes. In addition, some participants considered how patient rights and confidentiality may be affected by the development of national and international clinical databases. Twinning project activities were reported and recommendations for creating case-based data collection tools for use in various perinatal specialities were made.

Lastly, participants identified future goals for the project which include:

- Improve data reporting.
- Improve validity of reported data.
- Establish more twinning projects.
- Improve perinatal outcomes throughout the WHO European Region.

The Sixth OBSQID Workshop on quality development in perinatal care is tentatively scheduled to be held in conjunction with the EAPM meeting, which will take place 24–28 June 2000 in Oporto, Portugal.
Annexes

A. Scope and purpose
B. Programme
C. List of participants
D. Sample OBSQID basic information sheet and definitions, including WHO (five) well being index (1998 version)
E. Sample OBSQID perinatal aggregated data (PAD)
F. Sample neonatal basic information sheet
G. Draft basic information sheet for scanning
H. Draft basic information sheet for diabetes and pregnancy
Fifth Workshop on Quality Development in Perinatal Care

Nof Ginossar, 29-31 October 1998

SCOPE AND PURPOSE

Participants will discuss the outcomes of case-based data collection activities using the OBSQID Basic Information Sheet as it was revised at the Fourth OBSQID Workshop, with a view to establishing twinning activities linking centres demonstrating best practice with centres in need.

The activities conducted under twinning projects established at the Fourth Workshop will be presented by the participating centres, with special emphasis on results and improvements achieved in quality development in perinatal care as demonstrated by case-based data.

Participants will look at the implementation of electronic patient records using the EpiInfo data registration system, and discuss experiences in the use of this tool. In centres where no such facilities exist, solutions will be sought to introduce electronic patient record systems.

Perinatal aggregated data at local, regional and national levels has been facilitated through the implementation of an Internet data submission and analysis option. This will be demonstrated and discussed at the workshop.

The progress made in the development of a neonatal basic information sheet will be reviewed, as well as its links to the obstetrical sheet. Participants will suggest ways to promote the use of the sheet.

The role of data collection as a tool in perinatal quality of care development will be the subject of general discussion.
Fifth Workshop on Quality Development in Perinatal Care
Nof Ginossar, Israel, 29-31 October 1998

PROGRAMME

With the kind collaboration of the Perinatal Division and the WHO Collaborating Centre for Quality Management and Development in Perinatal Care, Rabin Medical Centre, Beilinson Campus, Sackler Faculty of Medicine, Tel Aviv University

Thursday, 29 October 1998

08.00-09.00 Registration

09.00-09.45 Welcome: background, purpose and expected outcomes of the workshop

Dr M. Hod (Host), Dr A. Samueloff (Chairman, Israeli Perinatal Society),
Dr K. Staehr Johansen (WHO)

Chairman’s Remarks: Prof Z. Ben Rafael (Honorary Chairman)
Rapporteur: Dr C. Sen

Short Speeches:

- Dr B. Lev (Ministry of Health of Israel)
- Prof K. Marsal (EAPM)
  The collaboration between WHO/EURO and the EAPM Study Group for Standardization of Birth Certificates and Perinatal Death Certificates: origins and underlying objectives.
- Dr G. Lindmark (FIGO)
  The work plan of the Perinatal Health Committee with respect to establishing a globally useful minimal perinatal data set.
- Dr K. Staehr Johansen (WHO)
  The goals and direction of WHO in Pan-European perinatal quality of care programs in the context of what has happened in the first five years of the OBSQID project and the new activities of EAPM and the FIGO. Where do we go from here?
09.45-10.15 Coffee break

10.15-10.30 Introduction to morning working group sessions:
Presenter: Dr T. Weber

10.30-12.00 Presentation and discussion of WHO/EURO data collection and analysis tools
Presenters:
- Mr V. Juncker: Paper-based data collection and fax submission
- Dr D. Pfeifer: Epilinfo: Introduction to the tool
- Dr R. Chen: The Israeli experience with Epilinfo implementation
- Mr V. Juncker: PAD data and Internet data analysis options
- Dr B. Marginitt: Operational management system in an obstetric service
- Dr Z. Ben Rafael: Computerized fetal monitoring

After the presentations, each speaker will be available to demonstrate these tools to small groups and hold discussion sessions. Participants may circulate among the sessions and are invited to comment on the tools and/or make suggestions for integrating OBSQID indicators and databases with data collection and analysis tools in use in their own countries or sites.

12.00-13.00 Practical experiences using the OBSQID BIS
Chairpersons: Prof J. Gadzinowski and Prof Z. Ben Rafael
Presenters:
- Dr P. Banfield
- Dr R. Chen
- Dr E. Charapova
- Prof J. Tofovski
- Dr P. Velebil

13.00-14.30 Lunch

14.30-15.30 Perinatal care in Europe: what are you doing in your country for data collection?
Chairpersons: Prof J. Tofovski and Prof H. Zion
Presenters:
- Dr C. Sen (Turkey)
- Mrs P. Zadka (Israel)
- Prof G. Mello and Prof F. Macacci (Italy)
- Dr H. Krohn (Portugal)
- Dr M. Szymankiewicz and Dr K. Kornacka (Poland)
- Dr J. Buinauskiene (Lithuania)
- Dr I. Abu Elaish (Palestinian Authority)

15.30-16.00 Discussion and coffee break

16.00-17.30 Working group sessions: experiences with pan-European case-based and perinatal aggregated data

WG 1: Experiences using the PAD, BIS and other data collection sheets
Moderators: Prof K. Marsal and Prof Z. Ben Rafael, Dr C. Savona-Ventura
This working group will examine the experiences of several countries that use standardized data collection forms to record case-based and/or aggregated perinatal data. Where no such forms exist, participants will discuss ways to introduce the OBSQID tools at their sites. Where such forms do exist, working group participants will review the data items on these forms and discuss how to incorporate OBSQID variables and indicators into their data sheets, how the data may be aggregated at data nodes, the obstacles encountered when introducing data collection systems to personnel at the local level and strategies for overcoming them.
WG 2: Using QCT databases for continuous quality and technology assessment
Moderators: Dr M. Ditte, Dr T. Weber, Prof H. Zion
Working group participants will focus on ways in which case based and aggregated data can be used to generate epidemiological data at the local, regional, or national level; identify best practices; and highlight specific areas in need of quality improvement. We will also point out ways in which this data can be used in an international context to successfully compete for needed financial and/or technological assistance. We will also discuss how to design national server networks which integrate data vertically from the local to regional to national levels while producing data which is comparable internationally.

WG 3: Designing and integrating perinatal Quality of Care Development (QCD) programmes into national QCD policies
Moderators: Dr B. Lev, Dr A. Samueloff
National policies on continuous quality of care development (QCD) exist in Denmark, Belgium and Slovenia, and are underway in other Member States. After a six-month study period of data collection and analysis, perinatal centres can be instrumental as models for the elaboration of such policies in their countries. On the basis of QCD activities in Slovenia as a model, participants will discuss their potential role in drafting, introducing and implementing a perinatal component within national QCD policies.

WG 4: Legal issues & confidentiality
Moderators: Dr D. Peleg, Dr K. Staehr Johansen
A key issue in data collection and analysis is confidentiality and respect for the legal and ethical rights of patients. This working group will discuss such issues and review how they have been dealt with in some Member States with a view to bringing successful legislation and experience gained to the fore.

17.30 – 18.00 Plenary session: reports from the working groups

Friday, 30 October 1998

09.00-10.00 A comprehensive approach to perinatal care in Europe – the Israeli example
Chairperson: Dr M. Hod
Presenters:
- Dr I. Yoles: Maternal mortality
- Dr B. Reichman: Outcomes of low birth weight babies (<1500gm)
- Dr P. Singer: The critically ill obstetric patient
- Dr A. Kimia: Extreme prematurity
- Dr A. Tzabari: Transport in utero
- Dr M. Hod: The macrosomic offspring

10.00-10.30 Discussion

10.30-10.45 Introduction to morning working group sessions: case based data in selected obstetric specialties
Presenter: Professor J. Gadzinowski
10.45-12.30 Working group sessions: case based data in obstetric specialities
(Coffee and tea will be provided)
Common, consensed indicators and variables with agreed definitions are a prerequisite for pan-European data comparison, analysis, benchmarking and twinning projects. Each working group will discuss the formulation of such indicators within their field of expertise with a view to producing Basic Information Sheets along the lines of the OSBQID BIS. At the Fourth Workshop, Professor J. Gadzinowski agreed to coordinate the elaboration of a NEOCARE BIS which is now available and will be presented in WG3 as a model for other specialities.

**WG 1 Diabetes in pregnancy**
*Moderators: Dr M. Hod, Dr H. Ilkova, Dr G. Tamas, Dr J. Wilczynski*

**WG 2 Multiple pregnancy**
*Moderators: Dr L. Keith, Prof A. Schoenfeld*

**WG 3 Neonatal care**
*Moderators: Prof A. Eidelman, Dr J. Mazela*

**WG 4 Hypertension in pregnancy**
*Moderators: Dr J. Bar Dr G. Breborowicz,

**WG 5 Transport in utero**
*Moderators: Dr I. Abu Elaish, Dr. A. Tzabari*

**WG 6 Blood transfusion**
*Moderators: Dr C. Russu*

**WG 7 Ultrasonography**
*Moderators: Dr C. Sen, Dr D. Sherman*

12.30-14.00 Lunch

14.00-14.45 Plenary: reports of morning working groups

14.45-15.15 Coffee/tea break

15.15-16.00 Introduction to the afternoon working group session: Twinning projects
*Chairpersons: Dr Ph. Banfield and Dr P. Velebil*
*Presenters:*

- The United Kingdom/Russia/Kyrgyzstan Twinning Project  
  *Dr Ph. Banfield, Dr E. Vikhlyaeva and Dr G. Asymbekova*
- The Poland/Ukraine Twinning Project  
  *Dr K. Kornacka*
- The Georgia/Israel Twinning Project  
  *Dr M. Hod and Dr N. Asatiani*

16.00 – 17.00 Working group sessions: Establishing new twinning projects

17.00-17.30 Summary and closure
Fifth Workshop on Quality Development in Perinatal Care

QCPH030203 1998/5

Nof Ginossar, 29 - 31 October 1998

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Regional Office for Europe

Ms Aletha Akers, Consultant
Dr Knud Alling-Møller, Consultant
Ms Lisa Copple, Programme Assistant
# OBSQID Basic Information Sheet

## Mother
- **Identification Code**
- **Residence**
  - Urban: O
  - Rural: O
- **Time to clinic**
  - Hours:Min:Sec: M
- **Mother's Year of Birth**
  - 19
- **Single**
  - Yes: O
  - No: O
- **Education**
  - University: O
  - Secondary: O
  - Primary: O
  - None: O

## Reproductive History
- **Abortion**
  - Spontaneous: O
  - Induced: O
  - Ectopic: O
- **Delivery**
  - Vaginal: O
  - Caesarean section: O
- **Outcome**
  - Number of live born: O
  - Number of preterm deliveries (<37 weeks): O
  - Number of early neonatal deaths: O
  - Number of late neonatal deaths: O
- **Violence during pregnancy**
  - Yes: O
  - No: O

## Well-Being
- **Score on the WHO/EURO well-being scale**
  - 5 weeks before expected delivery: O
  - 4 to 6 weeks after delivery: O
  - Mother: O
  - Father: O

## Present Pregnancy
- **Height (cm)**
- **Weight (kg) at delivery**
- **Weight gain (kg)**
- **Smoke**
  - Yes: O
  - No: O
  - Cigs. per day: O
- **Alcohol**
  - <=15 g/day: O
  - >15 g/day: O
  - (15 g=1 unit): O
- **Drug abuse**
  - Yes: O
  - No: O

## Ultrasound
- **Number of scanings**
- **First scan (week)**
- **Last scan (week)**
- **Scan for malformations**
  - Yes: O
  - No: O
- **Multiple gestation detected (week)**

## Pathology
- **If "Yes", please specify**
  - Threatened abortion: O
  - Threat premature labour: O
  - Antepartum haemorrhage (APH): O
  - Gestational hypertension: O
  - Pre-eclampsia: O
  - Eclampsia: O
  - Placenta praevia: O
  - Other: O

## Onset
- **Induced**
  - Yes: O
  - No: O
- **Spontaneous**
  - Yes: O
  - No: O
- **Planned CS**
  - Yes: O
  - No: O

## Delivery
- **Attended by**
  - Physician: O
  - Nurse/Midwife: O
  - Other: O
  - Unattended: O
- **Blood Transfusion**
  - Yes: O
  - No: O
  - Units: O
- **Maternal Discharge**
  - Home: O
  - Transferred: O
  - Dead: O
  - Days after delivery: O
  - Date of delivery (dd-mm-yy): O

## Analgesics
- **None**
- **Opioid**
- **Inhalation**
- **Regional**
- **Pudendal**
- **Other**

## Anaesthesia
- **None**
- **General**
- **Epidural/Spinal**
- **Other**

## Infant
- **General**
  - Infant number (multiple gestation): O
  - Sex
    - Male: O
    - Female: O
  - Birth weight
    - kg: O
    - g: O
  - Length: O
  - Head circum.:
    - cm: O
    - cm: O
  - Cord-blood pH at delivery: O
  - Artery: O
  - Vein: O
  - Unknown: O
- **Apgar**
  - 1 minute: O
  - 5 minutes: O
- **Feeding**
  - Breastfeeding in delivery room: O
  - Breast milk only: O
  - Infant formula: O
  - Formula and breast milk: O

## Infant Pathology
- **If "Yes", please specify**
  - Breech presentation at delivery: O
  - Transverse lie at delivery: O
  - Hydrops: O
  - Other: O
- **Congenital malformations**
  - (ICD-10 Code): O
  - Other (including infections): O

## Cause of Death
- **Congenital malformations**
  - Yes: O
  - No: O
- **Infertility**
  - Yes: O
  - No: O
- **Birth asphyxia/trauma**
  - Yes: O
  - No: O
- **Days after delivery**
  - O

## Discharge
- **Home**
  - Yes: O
  - No: O
- **Death**
  - Prenatal: O
  - Intrapartal: O
  - Postnatal: O

---

Filled in by: O

Revision 1 Mar 1999
# OBSQID Basic Information Sheet (BIS): Definitions

## Mother

| **Case Identification Code** | Code given to enable identification of the mother and access to her case history. It is obligatory to use it for multiple pregnancies in order to relate infant's outcome with course of pregnancy. If BIS forms are used by several institutions, data collected and typed into a database (not scanned), the code should include reference of the institution sending data, to enable analysis by sites. |
| **Residence** | Mother's permanent residence (urban or rural) |
| **Time to clinic** | The time it took for the mother to get to the clinic for the delivery in hours and minutes. For women who were hospitalised prior to the onset of delivery time to the clinic should be indicated as 00:00. If unknown leave blank |
| **Mother's Year of Birth** | The year in which the mother was born |
| **Single** | “Yes” indicates “Mother has no support at home to raise the infant”, not her marital status. |
| **Education** | Level at which education was stopped. |

## Reproductive History

<p>| <strong>Abortion</strong> | The termination of a pregnancy less than 22 completed weeks plus 0 days of gestation producing a dead fetus (&lt; 22 wks + 0 days). |
| <strong>Deliveries</strong> | Delivery of a liveborn infant or stillborn fetus more than or equal to 22 completed weeks plus 0 days of gestation (&gt;= 22wks + 0 days). See below for definition of “live born” and “still born”. |
| <strong>Outcome</strong> | This section refers to the outcome of past pregnancies. |
| <strong>Number of live born</strong> | Liveborn is the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of the pregnancy, which breathes or shows any other sign of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached. |</p>
<table>
<thead>
<tr>
<th>Number of still born</th>
<th>Stillborn or fetal death is death prior to the complete expulsion or extraction from its mother of a product of conception (more than or equal to 22 completed weeks of gestation + 0 days); the death is indicated by the fact that the fetus does not breathe or show any other sign of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of the voluntary muscles.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of preterm deliveries</td>
<td>The total number of live births delivered at less than 37 completed weeks of gestation (&lt; 37 gestational weeks + 0 days).</td>
</tr>
<tr>
<td>Number of early neonatal deaths</td>
<td>The early neonatal period commences at birth and ends 7 completed days after birth. The first day of life is Day 0, the second day is Day 1, as days are counted only when completed.</td>
</tr>
<tr>
<td>Number of late neonatal deaths</td>
<td>The late neonatal period commences at Day 7 and ends 28 completed days after delivery (end Day 27)</td>
</tr>
</tbody>
</table>

**Wellbeing**

<table>
<thead>
<tr>
<th>Well-Being</th>
<th>Ask the 5 questions from the WHO/PGWB Wellbeing Scale. Calculate the total and write the number in the appropriate box. Ask questions at 6 weeks before expected delivery and 6 weeks after delivery. If the mother and/or father are not available 6 weeks post delivery leave the wellbeing score blank.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Violence during pregnancy</td>
<td>&quot;Yes&quot; refers to pregnant women repeatedly subjected to forceful physical, social and psychological behaviour in order to coerce her, without regard to her rights. Battering includes slapping, kicking, punching, shoving, torture, and sexual assault. Women who are physically abused also suffer psychological and emotional abuse.</td>
</tr>
</tbody>
</table>

**Present Pregnancy**

<table>
<thead>
<tr>
<th>Pregnancy</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Height</td>
<td>Mother’s height in completed centimetres and barefooted, no decimals.</td>
</tr>
<tr>
<td>Weight at delivery</td>
<td>Mother’s weight indicated in kilograms, no decimals.</td>
</tr>
<tr>
<td>Weight gain</td>
<td>The difference between mother’s weight at delivery and prepregnancy weight, no decimals.</td>
</tr>
<tr>
<td>Number of prenatal visits</td>
<td>Total number of prenatal visits (with a midwife, nurse, physician, general practitioner or obstetrician).</td>
</tr>
<tr>
<td>Smoke</td>
<td>Smoking at any time during the pregnancy. Indicate if more than three cigarettes are smoked per day.</td>
</tr>
<tr>
<td>Alcohol</td>
<td>Alcohol consumption during pregnancy. Indicate if one or more drinks equivalent to 15 gr of alcohol (1 glass of beer or</td>
</tr>
<tr>
<td>Drug abuse</td>
<td>Abuse of drugs at any time during the pregnancy.</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>Multiple gestation detected</td>
<td>At which week was the diagnosis of multiple pregnancy made (ICD 10 code O30.0-30.9)</td>
</tr>
</tbody>
</table>

**Ultrasound**

<table>
<thead>
<tr>
<th>Number of scanings</th>
<th>The total number of ultrasound scanings performed during current pregnancy.</th>
</tr>
</thead>
<tbody>
<tr>
<td>First scan (week)</td>
<td>Indicate the completed number of weeks at which the first ultrasound scan was done.</td>
</tr>
<tr>
<td>Last scan (week)</td>
<td>Indicate the completed number of weeks at which the last ultrasound scan was done.</td>
</tr>
<tr>
<td>Second-level scan for malformations</td>
<td>Indicate if a second-level qualified scan was done for malformations.</td>
</tr>
</tbody>
</table>

**Pathology** (Multiple choice question)

<table>
<thead>
<tr>
<th>Threatened abortion</th>
<th>Bleeding of a woman with a pregnancy under 22 completed weeks of gestation (ICD 10 code O 20.0)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Threatened premature labour</td>
<td>Contractions and/or escape of amniotic fluid after 22 weeks plus 0 days and before 37 completed weeks of gestation (&gt;=22 wks + 0 days and &lt; 37 wks + 0 days) (ICD 10 code O 42, O 60)</td>
</tr>
<tr>
<td>Antepartum haemorrhage (APH)</td>
<td>Bleeding before labour (&gt;=22 wks of gestation + 0 days) (ICD 10 code O 46)</td>
</tr>
<tr>
<td>Placenta praevia</td>
<td>Indicate low implantation of (ICD 10 code O 44.0-44.1).</td>
</tr>
<tr>
<td>Placental abruption</td>
<td>Indicate presence of premature separation of placenta (ICD 10 code 45.0-45.9)</td>
</tr>
<tr>
<td>Gestational hypertension</td>
<td>Persistent hypertension greater than 140/90 (&gt;140/90), diagnosed during pregnancy with no proteinuria (ICD 10 code O13)</td>
</tr>
<tr>
<td>Pre-eclampsia</td>
<td>Gestational hypertension with proteinuria (ICD 10 code O14.0-O14.9)</td>
</tr>
<tr>
<td>Eclampsia</td>
<td>Convulsions related to hypertension and/or proteinuria before, during or after the delivery (ICD 10 code O15.0-15.9 plus eclampsia associated with O 10.0-14.9)</td>
</tr>
<tr>
<td>Suspected IUGR</td>
<td>Intrauterine growth retardation suspected during pregnancy (ICD 10 code O36.5). If ultrasound used in diagnosis of IUGR include fetuses with &gt; 20% deviation from normal growth curve.</td>
</tr>
<tr>
<td><strong>Blood group immunization</strong></td>
<td>Blood group antibodies that may cause fetal erythroblastosis (ICD 10 code O 36.0 or O 36.1)</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Assisted fertilisation (ART)</strong></td>
<td>Includes in vitro fertilisation (IVF), intracellular sperm injection (ICSI), or ovulation stimulation are performed to obtain the present pregnancy (ICD 10 code Z31.3 and Z 31.9). Intrauterine insemination (ICD 10 code 31.1) is excluded from the category.</td>
</tr>
<tr>
<td><strong>Infection</strong></td>
<td>Infection associated with an increased risk to the mother and/or infant (ICD 10 code O 23.0-23.9, O 26.4, O35.3, O 35.8, O 41.1, O 75.3, O 98.0-98.9)</td>
</tr>
<tr>
<td><strong>Cardiovascular disease</strong></td>
<td>Cardiovascular disease associated with an increased risk to the mother and/or infant (ICD 10 code O 99.4)</td>
</tr>
<tr>
<td><strong>Other diagnoses of pregnancies</strong></td>
<td>Other diagnosis of pregnancy is to be mentioned according to ICD 10 (International Statistical Classification of Diseases and Related Health Problems, 10th Revision, WHO), primarily from XV chapter of ICD 10 Pregnancy, childbirth and the puerperium, and when necessary use chapter XXI for antenatal screening or supervision during pregnancy.</td>
</tr>
<tr>
<td><strong>IDDM before pregnancy</strong></td>
<td>Insulin-dependent diabetes mellitus before conception (ICD 10 code O 24.0)</td>
</tr>
<tr>
<td><strong>NIDDM before pregnancy</strong></td>
<td>Non insulin-dependent diabetes mellitus before conception (ICD 10 code O 24.1)</td>
</tr>
<tr>
<td><strong>Gestational diabetes</strong></td>
<td>IDDM or NIDDM including diabetes diagnosed during pregnancy (ICD 10 code O 24.4 or O 24.9)</td>
</tr>
<tr>
<td><strong>Preconceptional treatment and Vascular complications</strong></td>
<td>to be answered with IDDM or NIDDM diagnosis</td>
</tr>
<tr>
<td><strong>Insulin treatment</strong></td>
<td>Note if insulin was administered for any kind of carbohydrate metabolism disturbance.</td>
</tr>
</tbody>
</table>

**Delivery**

**Onset** (How labour began. Single choice question.)

<table>
<thead>
<tr>
<th><strong>Induced</strong></th>
<th>by drugs (oxytocin or prostaglandins) or by artificial rupture of membranes.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Spontaneous</strong></td>
<td>Spontaneous onset of contractions with/without spontaneous rupture of membranes.</td>
</tr>
<tr>
<td><strong>Planned caesarean section</strong></td>
<td>Before onset of contractions and or spontaneous rupture of membranes (ICD 10 code O 82.0)</td>
</tr>
</tbody>
</table>
**Birth** (The mode of delivery that ended in birth of the infant. If more than one method has been attempted, only the last one that led to the delivery should be indicated. For multiple pregnancies note the mode of delivery for each infant on separate BIS form)

<table>
<thead>
<tr>
<th>Mode of Delivery</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaginal</td>
<td>Vertex delivery (ICD 10 code O80.0)</td>
</tr>
<tr>
<td>Forceps</td>
<td>Forceps delivery (ICD 10 code O81.0-81.3)</td>
</tr>
<tr>
<td>Vacuum</td>
<td>Ventouse delivery (ICD 10 code O81.4)</td>
</tr>
<tr>
<td>Assisted breech</td>
<td>Breech delivery (ICD 10 code O80.1, O83.0-83.1)</td>
</tr>
<tr>
<td>Elective Caesarean Section (CS) before labour</td>
<td>CS before labour planned more than 8 hours before the procedure (because of pregnancy or foreseeable delivery complications) (ICD 10 code O 82.0)</td>
</tr>
<tr>
<td>Acute CS before labour</td>
<td>CS planned less than 8 hours before labour because of pregnancy complications (ICD 10 code O 82.1).</td>
</tr>
<tr>
<td>Elective CS during labour</td>
<td>Elective CS was planned but labour began before the procedure (ICD 10 code O 82.0).</td>
</tr>
<tr>
<td>Acute CS during labour</td>
<td>Acute CS because of complications during labour (ICD 10 code O 82.1).</td>
</tr>
<tr>
<td>Calculated date of delivery (day/month/year) based on LMP</td>
<td>Indicate <em>either</em> LMP <em>or</em> US, single choice question</td>
</tr>
<tr>
<td></td>
<td>Last Menstrual Period used to identify infant’s gestational age</td>
</tr>
<tr>
<td>US</td>
<td>Ultrasound used to identify infant’s gestational age.</td>
</tr>
<tr>
<td>Certain</td>
<td>Indicate if infant gestational age is certain. If based on LMP, indicate ‘Certain’ as ‘Yes’ if there has been regular bleeding for 6 months before this pregnancy and oral contraceptives have not been used 3 months before this pregnancy. If based on US, identify as ‘Certain’ if US was before or at 20 completed weeks of gestation + 0 days.</td>
</tr>
</tbody>
</table>

**Attended by**

Indicate the highest level of health care provider present during the delivery, single choice question.

**Blood Transfusion**

Multiple choice question. Indicate if blood transfusion was ordered for 1) haemoglobin level less than or equal to 7 g/dl (of 4.3 mmol/L), 2) haematocrit level less than 21%, 3) clinical symptoms and 4) the units of blood administered (unit = one flacon, one plastic bag, irrespective of full blood or red cell concentrate)
Maternal Discharge  (Where mother went after discharge from the clinic of infant’s delivery, single choice question, home, transferred, dead.)

<table>
<thead>
<tr>
<th>Transferred</th>
<th>Mother was transferred to another medical department or institution.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dead</td>
<td>Maternal death within 42 days of delivery, irrespective of mother hospitalized at delivery hospital, transferred to another institution or discharged home (ICD 10 code O 95)</td>
</tr>
<tr>
<td>Days after Delivery</td>
<td>The number of days after delivery that the mother stayed in the clinic where she delivered before being discharged.</td>
</tr>
</tbody>
</table>

Special Conditions

<table>
<thead>
<tr>
<th>Episiotomy</th>
<th>Indicate if episiotomy was performed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lacerations</td>
<td>Perineal laceration during delivery (ICD 10 code O 70.0-70.9)</td>
</tr>
<tr>
<td>Rupture of membrane &gt; 24h</td>
<td>Membrane rupture more than 24 hours before delivery (ICD 10 code O 42.1)</td>
</tr>
<tr>
<td>Hysterectomy &lt; 48h</td>
<td>Hysterectomy performed 0 to 48 hours after delivery of the infant.</td>
</tr>
<tr>
<td>Retained placenta</td>
<td>Placenta, parts of the placenta, cotelydones or membranes were removed manually or by instruments (ICD 10 codes O 72.0, 72.2 and 73.0-73.1)</td>
</tr>
<tr>
<td>Bleeding &gt; 1000ml</td>
<td>Estimated bleeding of more than 1000 ml within 2 hours after delivery (ICD 10 code O 72)</td>
</tr>
<tr>
<td>Shoulder dystocia</td>
<td>Obstructed due to shoulder dystocia (ICD 10 code O 66.0)</td>
</tr>
<tr>
<td>Other diagnoses of labour and delivery</td>
<td>Other diagnosis of labour and delivery is to be mentioned according to ICD-10 Code (International Statistical Classification of Diseases and Related Health Problems, 10th Revision, WHO), primarily from XV chapter of ICD 10 Pregnancy, childbirth and the puerperium, and when necessary use chapter XXI for outcome of delivery</td>
</tr>
<tr>
<td>Date of delivery (dd/mm/yy)</td>
<td>Date of delivery-indicate day/month/year. Example: 15/01/97 is delivery on 15 January 1997</td>
</tr>
</tbody>
</table>

Infant

General

| Infant number       | For multiple births, based on chronological order, indicate infant’s number. Example, for twins, the first infant delivered is 1 of 2, the second infant delivered is 2 of 2, if single pregnancy indicate 1 of 1. Use separate BIS sheets for all consecutive infants originating from multiple pregnancy |

6 OBSQID BIS definitions: Revision 1 April 1998
<table>
<thead>
<tr>
<th><strong>Sex</strong></th>
<th>Indicate if infant is M=male or F=female.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Birthweight</strong></td>
<td>Infant’s weight given in grams, no decimals.</td>
</tr>
<tr>
<td><strong>Length</strong></td>
<td>Length of infant given in completed centimetres, no decimals</td>
</tr>
<tr>
<td><strong>Head Circum</strong></td>
<td>Head circumference of infant given in completed centimetres.</td>
</tr>
<tr>
<td><strong>Cord blood pH</strong></td>
<td>pH analysis of blood drawn from the umbilical cord after delivery.</td>
</tr>
<tr>
<td><strong>Breech presentation at delivery</strong></td>
<td>The fetal position at delivery.</td>
</tr>
<tr>
<td><strong>Transverse lie at delivery</strong></td>
<td>The fetal position at delivery.</td>
</tr>
<tr>
<td><strong>Apgar</strong></td>
<td>Infant’s score at 1 minute and 5 minutes after birth. 0/0 indicates stillborn infant. If Apgar score unknown leave blank.</td>
</tr>
</tbody>
</table>

**Feeding**

| **Breast milk** | Infant fed ONLY breast milk before discharge from the clinic. |
| **Infant formula** | Infant fed ONLY infant formula before discharge from the clinic. |
| **Formula and breast milk** | Infant fed breast milk AND infant formula before discharge. |

**Pathology**

<p>| <strong>RDS/Hyaline membrane</strong> | Respiratory Distress Syndrome. |
| <strong>Other resp conditions</strong> | Other respiratory conditions of the infant. After ≥37 weeks of gestation, unexplained apnea and/or cyanoses. |
| <strong>Seizure within 7 days</strong> | Episodes within 7 days. For example: serial or single convulsions, if possible verified by EEG, EEG spikes without clinical symptoms |
| <strong>Hyperbilirubinaemia</strong> | Clinical jaundice leading to phototherapy or exchange transfusion |
| <strong>Sepsis</strong> | Positive culture based on blood |
| <strong>Congenital Malformations</strong> | Identify most serious congenital malformation. |
| <strong>Other</strong> | Any pathology of the infant not mentioned in the above list. Use to ICD-10 Code (International Statistical Classification of Diseases and Related Health Problems, 10th Revision, WHO), XVI chapter of ICD 10 Pregnancy, Certain conditions originating in the perinatal period. |
| <strong>Cause of Death</strong> | Indicate cause of death, or findings on autopsy from list provided. Multiple choice question. |
| <strong>Discharge</strong> | Where infant was to go when released from the clinic: home, transferred to a department or institution such as a paediatric |</p>
<table>
<thead>
<tr>
<th>Description</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>or a neonatal department or</td>
<td>or a neonatal department or died irrespective if it was initially</td>
</tr>
<tr>
<td>died irrespective if it was</td>
<td>discharged home or transferred. If dead indicate whether perinatal,</td>
</tr>
<tr>
<td>initially discharged home</td>
<td>intranatal or postnatal death.</td>
</tr>
<tr>
<td>or transferred.</td>
<td></td>
</tr>
<tr>
<td><strong>Days after delivery</strong></td>
<td>Number of days infant was in the clinic of delivery before discharge or</td>
</tr>
<tr>
<td></td>
<td>before it died.</td>
</tr>
<tr>
<td><strong>Filled in by</strong></td>
<td>For clinic use to identify person filling in the BIS form.</td>
</tr>
<tr>
<td><strong>Revision ... 1998</strong></td>
<td>Date of most recent revision of the BIS.</td>
</tr>
</tbody>
</table>
**WHO (Five) Well Being Index (1998 version)**

Please indicate for each of the five statements which is closest to how you have been feeling over the last two weeks. Note that higher numbers mean better well-being.

*Example:* If you have felt *cheerful and in good spirits* more than half of the time during the last two weeks, put a tick in the box with the number 3 in the upper right corner.

<table>
<thead>
<tr>
<th>Over the last two weeks</th>
<th>All of the time</th>
<th>Most of the time</th>
<th>More than half of the time</th>
<th>Less than half of the time</th>
<th>Some of the time</th>
<th>At no time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have felt cheerful and in good spirits</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>2. I have felt calm and relaxed</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>3. I have felt active and vigorous</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>4. I have felt fresh and rested when I wake up</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>5. My daily life has been filled with things that interest me</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

**Scoring Instructions.**

To calculate your score, add up the numbers in the upper right corner of the squares you marked and multiply the sum by four.

You will then get a score ranging from 0 to 100. A higher score signifies greater well-being.
<table>
<thead>
<tr>
<th>Women who gave birth (deliveries)</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Infants born (births)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Intrauterine deaths (22-27 completed weeks)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Antenatal deaths (&gt;27 completed weeks)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total antenatal death if 1/2 not available</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Fetal deaths during delivery</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Early neonatal death (0-6 days)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Late neonatal death (7-27 days)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total neonatal death if 4/5 not available</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Preterm birth (&lt;32 completed weeks)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Preterm birth (32-36 completed weeks)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Major congenital malformations</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Lethal congenital malformations</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Apgar &lt;=6 @ 5 minutes (&gt;31 completed weeks)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Infants with RDS</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please print your information using only the following characters and avoid contact with the edge of the box.

Example: `0123456789` NOT `!` or `?`
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>12. Neonatal seizures within 7 days</strong></td>
<td></td>
</tr>
<tr>
<td><strong>13. Maternal deaths within 42 days</strong></td>
<td></td>
</tr>
<tr>
<td><strong>14. Hysterectomy within 48 hours</strong></td>
<td></td>
</tr>
<tr>
<td><strong>15. Women with blood transfusion</strong></td>
<td></td>
</tr>
<tr>
<td><strong>16. Eclampsia (during pregnancy - 10 days after delivery)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>17. Women with multiple pregnancies</strong></td>
<td></td>
</tr>
<tr>
<td><strong>18. Multiple pregnancies detected before delivery</strong></td>
<td></td>
</tr>
<tr>
<td><strong>19. Parturients with no prenatal visits before birth</strong></td>
<td></td>
</tr>
<tr>
<td><strong>20. Births unattended by health care provider</strong></td>
<td></td>
</tr>
<tr>
<td><strong>21. Caesarean sections</strong></td>
<td></td>
</tr>
<tr>
<td><strong>22. Forceps extractions</strong></td>
<td></td>
</tr>
<tr>
<td><strong>23. Vacuum extractions</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Forceps+Vacuum extractions if 22/23 not available</strong></td>
<td></td>
</tr>
<tr>
<td><strong>24. Insulin dependent diabetes mellitus</strong></td>
<td></td>
</tr>
<tr>
<td><strong>25. Non-insulin dependent diabetes mellitus</strong></td>
<td></td>
</tr>
<tr>
<td><strong>26. Gestational diabetes mellitus</strong></td>
<td></td>
</tr>
</tbody>
</table>

*All data are to be entered as absolute numbers.* For example, if you already have calculated a percentage or a rate in any field, please back-calculate and fill in the 'raw' number. *Do not use special characters like Ø, /, ?, - or *. Avoid leading zeros. *If data are unavailable please leave the field empty.*
<table>
<thead>
<tr>
<th>Section</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification number</td>
<td></td>
</tr>
<tr>
<td>Gestational age</td>
<td></td>
</tr>
<tr>
<td>Infant number</td>
<td></td>
</tr>
<tr>
<td>Apgar</td>
<td></td>
</tr>
<tr>
<td>Last name (not read)</td>
<td></td>
</tr>
<tr>
<td>Mother's name (not read)</td>
<td></td>
</tr>
<tr>
<td>Mother's age</td>
<td></td>
</tr>
<tr>
<td>Gravida</td>
<td></td>
</tr>
<tr>
<td>Para</td>
<td></td>
</tr>
<tr>
<td>Head circ.</td>
<td></td>
</tr>
<tr>
<td>Length</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td></td>
</tr>
<tr>
<td>Hair vessel</td>
<td></td>
</tr>
<tr>
<td>Artery</td>
<td></td>
</tr>
<tr>
<td>First hour of life gases</td>
<td></td>
</tr>
<tr>
<td>BE</td>
<td></td>
</tr>
<tr>
<td>Inborn</td>
<td></td>
</tr>
<tr>
<td>Outborn</td>
<td></td>
</tr>
<tr>
<td>Date of admission</td>
<td></td>
</tr>
<tr>
<td>Time of admission</td>
<td></td>
</tr>
<tr>
<td>Date of delivery</td>
<td></td>
</tr>
<tr>
<td>Time of delivery</td>
<td></td>
</tr>
<tr>
<td>Respiratory care</td>
<td></td>
</tr>
<tr>
<td>CRIB score</td>
<td></td>
</tr>
<tr>
<td>Mechanical ventilation</td>
<td></td>
</tr>
<tr>
<td>HFOV/jet ventilation</td>
<td></td>
</tr>
<tr>
<td>CPAP</td>
<td></td>
</tr>
<tr>
<td>On oxygen</td>
<td></td>
</tr>
<tr>
<td>NO treatment</td>
<td></td>
</tr>
<tr>
<td>Intubations</td>
<td></td>
</tr>
<tr>
<td>Chest tube</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td></td>
</tr>
<tr>
<td>(ICD10 codes)</td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
<td></td>
</tr>
<tr>
<td>Antibiotics</td>
<td></td>
</tr>
<tr>
<td>EPO</td>
<td></td>
</tr>
<tr>
<td>Immunoglobulines</td>
<td></td>
</tr>
<tr>
<td>Indomethacin</td>
<td></td>
</tr>
<tr>
<td>Inotropics</td>
<td></td>
</tr>
<tr>
<td>Methylene xanthine</td>
<td></td>
</tr>
<tr>
<td>Steroids for CLD</td>
<td></td>
</tr>
<tr>
<td>Vasopressors</td>
<td></td>
</tr>
<tr>
<td>Infection (sepsis/meningitis)</td>
<td></td>
</tr>
<tr>
<td>Early</td>
<td></td>
</tr>
<tr>
<td>=&gt; Viral</td>
<td></td>
</tr>
<tr>
<td>Late</td>
<td></td>
</tr>
<tr>
<td>=&gt; Viral</td>
<td></td>
</tr>
<tr>
<td>Prevention</td>
<td></td>
</tr>
<tr>
<td>Vitamin K</td>
<td></td>
</tr>
<tr>
<td>Tuberculosis</td>
<td></td>
</tr>
<tr>
<td>Hepatitis B</td>
<td></td>
</tr>
<tr>
<td>RSV</td>
<td></td>
</tr>
<tr>
<td>Haemophilus E</td>
<td></td>
</tr>
<tr>
<td>Screening</td>
<td></td>
</tr>
<tr>
<td>Pos</td>
<td></td>
</tr>
<tr>
<td>Neg</td>
<td></td>
</tr>
<tr>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>PKU</td>
<td></td>
</tr>
<tr>
<td>Hypothyreosis</td>
<td></td>
</tr>
<tr>
<td>Toxoplasmosis</td>
<td></td>
</tr>
<tr>
<td>Cytomegalovirus</td>
<td></td>
</tr>
<tr>
<td>Drug meconium/urine</td>
<td></td>
</tr>
<tr>
<td>Hip dislocation (US)</td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Bact. strain</td>
<td></td>
</tr>
<tr>
<td>I</td>
<td></td>
</tr>
<tr>
<td>II</td>
<td></td>
</tr>
<tr>
<td>III</td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td></td>
</tr>
<tr>
<td>V</td>
<td></td>
</tr>
<tr>
<td>VI</td>
<td></td>
</tr>
<tr>
<td>VII</td>
<td></td>
</tr>
<tr>
<td>VIII</td>
<td></td>
</tr>
<tr>
<td>Date of 36 weeks adjusted gestational age</td>
<td></td>
</tr>
<tr>
<td>Discharge</td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td></td>
</tr>
<tr>
<td>Transferred</td>
<td></td>
</tr>
<tr>
<td>Stillbirth</td>
<td></td>
</tr>
<tr>
<td>Dead</td>
<td></td>
</tr>
<tr>
<td>Reason for transfer</td>
<td></td>
</tr>
<tr>
<td>Weight</td>
<td></td>
</tr>
<tr>
<td>Days after delivery</td>
<td></td>
</tr>
<tr>
<td>Suplemental oxygen</td>
<td></td>
</tr>
<tr>
<td>Cardiometer</td>
<td></td>
</tr>
<tr>
<td>Breast fed</td>
<td></td>
</tr>
<tr>
<td>Breast milk fed</td>
<td></td>
</tr>
<tr>
<td>Formula fed</td>
<td></td>
</tr>
</tbody>
</table>
Basic Information Sheet for Scanning

<table>
<thead>
<tr>
<th>Data set number</th>
<th>Country/Centre name</th>
<th>Physician</th>
<th>Date of record</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surname</td>
<td>Name</td>
<td>Date of Birth</td>
<td>Single Yes No</td>
</tr>
<tr>
<td>Residence</td>
<td>Urban Rural</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Distance from Clinic (km)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Term Delivery
- Preterm Delivery 28-37 w
- 24-28 w
- Abortion <12 w
- >12 w

Previous anomaly: Obstetric History: Maternal disease: 

PREGNANT

Early scanning for pregnancy confirmation at

<table>
<thead>
<tr>
<th>w CRL: mm</th>
<th>Abortion at weeks</th>
<th>Induced</th>
<th>Spontaneous</th>
</tr>
</thead>
<tbody>
<tr>
<td>10-14 weeks scanning</td>
<td>NTD</td>
<td>Omphalocele</td>
<td>D.Hernia</td>
</tr>
<tr>
<td>w CRL: mm</td>
<td>NT: mm</td>
<td>PAPP-A free-beta hCG</td>
<td>Calculated risk for chr. Abn</td>
</tr>
<tr>
<td>Intervention: AS</td>
<td>CVS</td>
<td>Embryoscopy</td>
<td></td>
</tr>
</tbody>
</table>

| Abortion at weeks | Induced / Spontaneous |

<table>
<thead>
<tr>
<th>16-18 w weeks scanning</th>
<th>w BPD mm</th>
<th>HC: mm</th>
<th>AC: mm</th>
<th>FL: mm</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stomach:</td>
<td>Kidneys</td>
<td>Abd.wall</td>
<td>Brain and neural tube</td>
<td>Extremities</td>
</tr>
<tr>
<td>Amnios</td>
<td>Placenta</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Triple test:</td>
<td>risk estimation for chr. abn.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intervention: AS</td>
<td>CVS</td>
<td>FBS</td>
<td>Fetoscopy</td>
<td>Other</td>
</tr>
</tbody>
</table>

| Indication: |

| Please specify if any abnormality: |

| Abortion at weeks | Induced / Spontaneous |

<table>
<thead>
<tr>
<th>22-24 weeks scanning</th>
<th>w BPD mm</th>
<th>HC: mm</th>
<th>AC: mm</th>
<th>FL: mm</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stomach:</td>
<td>Kidneys</td>
<td>Abd.wall</td>
<td>Brain and neural tube</td>
<td>Extremities</td>
</tr>
<tr>
<td>Notch:</td>
<td>Amnios</td>
<td>Placenta</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intervention: AS</td>
<td>CVS</td>
<td>FBS</td>
<td>Fetoscopy</td>
<td>Other</td>
</tr>
</tbody>
</table>

| Indication: |

| Please specify if any abnormality: |

| Abortion at weeks | Induced / Spontaneous |

IF YOU NEED, YOU CAN USE MORE SHEET FOR EXTRA SCANNING

<table>
<thead>
<tr>
<th>32 weeks scanning</th>
<th>w BPD mm</th>
<th>HC: mm</th>
<th>AC: mm</th>
<th>FL: mm</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stomach:</td>
<td>Kidneys</td>
<td>Abd.wall</td>
<td>Brain and neural tube</td>
<td>Extremities</td>
</tr>
<tr>
<td>Amnios</td>
<td>Placenta</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intervention: FBS IUT</td>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Indication: |

| Please note the results of Doppler if studied |

| Please specify if any abnormality: |

<table>
<thead>
<tr>
<th>38 weeks scanning</th>
<th>w BPD mm</th>
<th>HC: mm</th>
<th>AC: mm</th>
<th>FL: mm</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stomach:</td>
<td>Kidneys</td>
<td>Abd.wall</td>
<td>Brain and neural tube</td>
<td>Extremities</td>
</tr>
<tr>
<td>Amnios</td>
<td>Placenta</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intervention: FBS IUT</td>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Indication: |

| Please note the results of Doppler if studied |

| Please specify if any abnormality: |

Birth
- Stillbirth Labor Spontaneous Induced Instrumented C/S

| Maternal outcome |

| Birth: |
|-----------------|--------|--------|--------|---|
| Sex: |
| Birth weight: | Length: | Head circ: |

| Neonatal outcome: |

Apgar-1: Apgar-2: pH:

COMMENTS:
### Basic Information Sheet for Diabetes and Pregnancy

#### Data Set Number: [ ]
#### Country: [ ]
#### Centre Name: [ ]
#### Treating Physician: [ ]
#### Date of Record: [ ]

### Basic Personal Data

- **Family Name:** [ ]
- **Given Name:** [ ]
- **Date of Birth:** [ ]
- **Residence:** [ ] Urban [ ] Rural
- **Distance from Clinic (km):** [ ]
- **Ethnicity:** [ ]

### Diabetes Diagnosis

- **Type of Diabetes:**
  - [ ] IDDM
  - [ ] Pre-GDM
  - [ ] NIDDM
  - [ ] GDM
  - [ ] IGT
  - [ ] G-IGT

#### Diagnosis Based on:

<table>
<thead>
<tr>
<th>Option</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>[ ]</td>
<td>Blood glucose: fasting or postprandial</td>
</tr>
<tr>
<td>[ ]</td>
<td>GTT (50g)</td>
</tr>
<tr>
<td>[ ]</td>
<td>oGTT (75g)</td>
</tr>
<tr>
<td>[ ]</td>
<td>oGTT (100g)</td>
</tr>
<tr>
<td>[ ]</td>
<td>Test meal</td>
</tr>
<tr>
<td>[ ]</td>
<td>Unknown</td>
</tr>
</tbody>
</table>

- **Diagnosis:**
  - **Date:** [ ]
  - **Gestational Week:** [ ]

- **Previous Pregnancies:**
  - [ ] Induced Abortions

- **Total Live Births:** [ ]
- **Stillbirths:** [ ]
- **Early Neonatal Mortality:** [ ]
- **Late Infant Mortality:** [ ]
- **Deaths in First Year:** [ ]
- **Pregnancy with Diabetes:** [ ]
- **Born with Major Malformation:** [ ]

### Past Obstetrical History

#### Pre-Pregnancy Counselling

- **Prepregnancy Counselling:**
  - [ ] Yes
  - [ ] No
- **Structured Information:**
  - [ ] Yes
  - [ ] No

#### Booking

- **Date of First Visit to the Specialist:** [ ]
- **Planned Pregnancy:**
  - [ ] Yes
  - [ ] No

#### Mother

- **Therapy:**
  - [ ] Insulin
  - [ ] Diet

- **Gestational Week of Delivery:** [ ]
- **Weight Gain in Pregnancy:** [ ]
- **Self Measure BG/Whk Last Trimester:** [ ]

- **Severe Hypos:** [ ]
- **Ketocidotic Episodes:** [ ]
- **Acute Urinary Tract Infections:** [ ]
- **Chronic Hypertension:**
  - [ ] Yes
  - [ ] No
- **Chronic HT and PIH:**
  - [ ] Yes
  - [ ] No
- **Pregnancy Induced Hypertension (PIH):**
  - [ ] Yes
  - [ ] No

### Birth

- **Stillbirth:**
  - [ ] Yes
  - [ ] No

#### Labour

- **Abortion:**
  - [ ] Induced
  - [ ] Spontaneous
- **Spontaneous Labour:** [ ]
- **Instrument Used:**
  - [ ] Yes
  - [ ] No

#### Cesarean Section

- **Primary:** [ ]
  - [ ] Yes
  - [ ] No
- **Secondary:** [ ]
  - [ ] Yes
  - [ ] No

### Newborn

- **Male:** [ ]
  - [ ] Female
- **Neonatal Weight:** [ ]
- **Length:** [ ]
- **Head circle:** [ ]
- **pH:** [ ]

#### Discharge

- **Healthy:** [ ]
- **Ill:** [ ]
- **Dead:** [ ]

#### Congenital Malformations

<table>
<thead>
<tr>
<th>Malformation Type</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NTD</td>
<td></td>
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</tr>
</tbody>
</table>

#### Pathologies

<table>
<thead>
<tr>
<th>Pathology Type</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obstructive Trauma</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Neonatal Asphyxia</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Severe Hypoglycaemia</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Hyperbilirubinaemia</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Polycythemia</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Skeletal Abnormality</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Other</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

#### Feeding

- **Breast:** [ ]
- **Bottle:** [ ]

### Reclassification

- **Has the Type of Diabetes Been Reclassified?**
  - [ ] Yes
  - [ ] No

#### New Classification

- **IDDM**
  - [ ] No diabetes
  - [ ] Type unknown
- **NIDDM**
  - [ ] Potential abnormality of glucose tolerance
  - [ ] Not known if reclassification done
- **IGT**
  - [ ] Normal glucose tolerance

#### Reclassification Based on

- **Elevated Blood Glucose**
  - [ ] Yes
  - [ ] No
- **oGTT (75g)**
  - [ ] Yes
  - [ ] No
- **Other**
  - [ ] Yes
  - [ ] No