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## Round Table Two

# Perinatal epidemiology in Switzerland Agenda for the future

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**FP:** *At the beginning of the meeting Prof. Duc asked what was the purpose of this meeting. This is a good question. The purpose of epidemiologic surveillance, in general, is to make decisions, and this has important implications. The kind of decisions we have to make with a perinatologic surveillance are decisions to be taken at the community level. Because of our scarce resources, it is becoming extremely important to base our decisions on good information, which means that we need a well designed information system. There is large room for improvement in Switzerland, as in many other countries, in the design of information systems, providing data of good quality. Last but not least, the decision makers in the country have to be informed about these epidemiologic data. As pointed out by Prof. Duc, I am not sure that relevant information, such as the papers presented her today, really reach the decision makers, who allocate resources. This is probably one of the most important things we have to think about: how can we make our studies available to those who make the decisions?*
*The second point that I wanted to make is that epidemiologic surveillance does not have to be based on exhaustive surveys: There are several methods to sample data, i.e. by reporting them every 2,3 or even 10 years. Or we can limit ourselves to a specific segment of population. We have heard today about studies made on specific segments of live births, for example extremely low birth weight babies and multiple gestations. Another point of importance is that routine statistics should not be limited to counting deaths, although I admit that epidemiologists are "biased towards death" because it is an event very easy to deal with. Some of you today have expressed the view that perinatal death is not a point of major interest any more. For the future, epidemiology is also important in counting other events such as morbidity. Finally, epidemiology is not only able to count events, it is also a method for designing information systems. Close collaboration between epidemiologists and clinicians, pathologists, and others, is very fruitful in this respect.*
*We have several people involved in perinatal practice here at this Round Table, and I would like to ask each of them to respond briefly to three questions, and then we will open the discussion with the audience.*
*First question: We heard this afternoon several important reports from ongoing epidemiological surveys. Which important areas of perinatal epidemiology should still be covered in Switzerland? Please limit your answer to two areas of greatest interest.*
*Second question: What pieces of information should be added to the existing routine statistics? We already have some indications from*

*the Round Table of this morning, especially from Thomas Spuhler. Regarding new information, gestational age was mentioned, as was place of delivery. We could speak of social items which were suppressed unexpectedly in the last revision. We also spoke about better information on the existing official birth certificate, I don't know if changing the couse of death code is a question to be considered. Here also, please two suggestions only.*
*Third question: What are the most urgently needed resources to maintain and to develop in perinatal epidemiology in Switzerland, and how can we best organize this kind of resources in our country?*
*I would like to start with Dr. Briner from Zürich, who hasn't spoken yet today.*

**JB:** Before I start answering these questions, I would like to make a few statements. I have been in charge of pediatric pathology in Zürich for 15 years. We have around 300 pediatric and fetal autopsies per year, of which 70 are in neonatal patients. We carry out the autopsies according to standard procedures, including placental examination as many times as possible. We appreciate very much to have the audit, a monthly meeting with the clinicians, neonatologists, gynecologists, surgeons as well as the geneticists, where we discuss the most important cases. Two assistants receive a one-year training in pediatric pathology; the residents in general pathology work on a rotating basis for 3 months in our pediatric pathology section.
One of the problems in pediatric pathology in Switzerland is that we only have a few colleagues who are specialized in the field. However, there is a large number of persons in several institutions interested in pediatric pathology. We have a well organized group of Swiss pediatric pathologists, who meet on a regular basis, and if a problem is coming up, we discuss cases, problems and projects. If there are interesting projects suggested by this group meeting here today, there certainly will be the possibility of teaming up with our group. The Swiss pediatric pathology group already offered training by providing curses for our colleagues. We have done this for pediatric tumors and molecular biology techniques. Now coming back to your questions.
We pathologist can provide you with important data, and we are happy to do so, but the main thing is to be very clear about what you want. Even before you get the results, you should know what you are going to do with them. Organizing a nation-wide project should keep in mind the obstacles of our federalistic state in Switzerland, and should therefore be done jointly (remember the problem of Eurocat registrations). Concerning development in research, pediatric pathologists can help by carrying on courses and giving good training opportunities at the universities. We can foster joint meetings with our clinicians. One thing which we can do concerning research is we can provide training to use the modern tools of research, including molecular biology, keeping in mind that the same principles that apply to oncogenesis also apply to teratogenesis. Now, about the standard pieces of information: the information should be standardized and collected on a nationwide basis. In some cantons the necessary information is available but on a nationwide basis, we certainly don't have it. You mentioned the cause of death in your opening statement. I think not just the cause of death should be of interest, but all the important diagnoses, including complications. If we are providing diagnoses as accurate as possible, it is easy to group them according to any classification, including the one proposed by Prof. Wigglesworth.

**FP:** *Thank you very much for your suggestions.*

**AC:** I will try to answer specifically the three questions asked by Fred Paccaud, from a neonatologist's point of view. Concerning the first question, we all agree that gestational age is a very important item and that we must have some knowledge of the incidence and trends of prematurity in Switzerland. The second important point is to get some consensus on which items of morbidity and outcome we should collect. I think that in terms of research and development, it is important to have a discussion on this point.
To the second question, we had only two options, so I chose gestational age of course, and my second choice would be some kind of information on the utilization of health services in the neonatal period, for instance neonatal hospitalization in NICU (Neonatal Intensive Care Unit) or PICU (Pediatric Intensive Care Unit).
To the third question, about resources, two prerequisites are very important: the coordination of data collection between the different participants, and a good collaboration between clinicians and epidemiologists.

**FP:** *Thank you very much...,*
*Dr. Spuhler please.*

**TS:** This morning I proposed the same two additional items, as proposed by Dr. Calame now. They are urgently needed. In my view, we could actually expand our data base much more. This would limit the additional efforts which are currently needed when one sets up the infrastructure of special studies. Typically, we have an epidemic of ophthalmopathia, then we set up a registration system. We have a problem with malformations, we set up a registration system, etc. Perhaps, with some consensus from those involved in

perinatal care, we could arrive to a system which could give us some basic general information and could serve as a tool, for not only national statistics, which for me is one but not the most important objective, but serve as a tool for answering such important public health questions: Can we treat those who need treatment? How is the health status of our children at birth and afterwards?
We could also need a data base which could be used by the clinicians for follow-up. We have several teams in Switzerland who do follow-up studies form within a clinical setting. This is an essential requirement, I think, because those who have to fill in the questionnaires should be convinced that they answer the right questions. They are at the front, we are back at the office. I think the highest priority is to make use of our data. Clinicians should use and know what is in our data bases.

**FP:** *Thank you Thomas, especially for the last sentence..., Prof. Schneider.*

**HS:** As clinicians involved in perinatal medicine, we are faced with everyday problems, and our major problem right now is the shortage in capacity we have in neonatal intensive care. I think the research in perinatal epidemiology should really provide te material for us to solve this problem, that seems to me right now the most pressing issue. We would need more precise data of the nature as Dr. Paneth has described so nicely to us this morning, so we have an idea of how well our perinatal referral system is working. Thomas Spuhler has been of great help to give us some first information on the canton of Berne. Research along those lines should be intensified so that we can point out our needs to the politicians who are responsible for the distribution of the resources. The politicians nowadays will not act, and they should not act, without prior very solid documentation of the needs, because they have to set priorities. And in order to set the priorities they have to have the solid information and documentation from us. There should be a major emphais on that type of research.
As far as data collection is concerned, I would like to stress what I have said earlier, I think there should be a serious attempt to expand on the vital statistics data because that is the only chance of really getting some sort of population-based meaningful data. Maybe the federal office of statistics should form a little expert group (epidemiologists, clinicians, pathologists) to discuss which would be the few data most needed, and how to include these data into a reviewed form of the birth certificate. I know there are many frustrated and discouraged people here, who have tried to work in that direction. I think some things need time to mature and it doesn't mean that when it has failed 10 years ago that it shouldn't be tried again now.
As far as a more extensive obstetrical data collection, on an ongoing basis, is concerned, it only has a chance of success when the amount of data is reduced to a reasonable number of items. People have to be convinced of the usefullness of these data, they should have access to these data. We, as obstetricians, should think about some sort of coordinated collection of a selected number of data which would be done in a decentralized fashion, but each institution would provide comparable data. In addition to making use of their own data, they should be repared to feed them into a central data bank, so that more population based conslusions could be drawn.
I would like to warn against false expectations, that from a data bank one can answer all types of research questions. I think that is a false attitude, which is very widespread. Most research questions will have to be answered on a prospective basis and the data collection will have to be designed according to a specific research question. That must be done on a prospective basis, over a limited period of time. Ongoing data collection is of limited value to answer very specific research question. They provide a different kind of information.

**FP:** *Thank you very much for these very insightful somments. Ursula...?*

**UA:** I will try to summarize what I think at this point, and has been said by many others already. There are two lines of research, or statistics, that should be done. One is the official statistics, where we need data on everybody. This can only be done through the vital statistics. We also need more information, or standardized information, on all those who go through specialized clinical services. The proposal made by Dr. Fawer impressed me very much, as a tool where all neonatal units could collect the same data and add their own research question into it. The efforts that have been done in the past by Prof. Duc could be continued and made a little easier in the future. This is a very valuable effort and it should have a high priority.
As for the standard certificates, not only the birth certificate should be changed, but also the death certificates for children. I would like to have gestational age in the birth certificate, a malformation code, which I have been discussing a long time ago, and socio-economic status should be re-introduced. The code for socio-economic status was dropped unfortunately, although we clearly showed that socio-economic status plays a major role in infant and perinatal mortality in Switzerland. Some of the information that are on the certificate should be changed: Place of birth

should be categorized in more details. Number of children should be changed to indicate not only children in the current marriage, but in terms of parity. That would better allow comparison with other statistics, worldwide, and would be more useful to evaluate what is happening in our country. On the infant death certificate, there should be a code for place of death to indicate whether death occured in a neonatal unit, and whether the infant was transfered before death or not. That would be easy to introduce. Therefore, a group should be set up to decide which changes should be made. Concerning resources, some of the statistics should be done more efficiently, and be published more officially. That's my last and most urgent wish.

**FP:** *Thank you very much. I think that was a bulk of very usefull suggestions. I don't want to sum up now, but open the discussion with the audience.*

**Jeremiah Cox:** I have one question for Prof. Wigglesworth. Why has the placenta been completly omitted in the former British studies?

**Jonathan Wigglesworth:** I presume because the people who designed the British studies weren't interested in the placenta. They probably didn't know it existed... A lot of obstetricians send us fetuses without placentas, there is a lot of ignorance that the placenta actually does have a function. I am sure it's not only in Britain.

**Thomas Pexieder:** I would like to ask a question to Prof. Schneider. From the point of view of the monitoring of environmental effects, one of the most sensitive indicators is the rate of spontaneous abortions. Can you tell me, as an obstetricians, how could we record in a simple way spontaneous abortions in Switzerland?

One of the purposes of monitoring congenital abnormalities is to have an early warning system. The very first thing which would change after a teratogen exposure would be the abortion rate.

**HS:** As far as the abortion statistics is concerned, that is of course very difficult because you have to make a definition of what a spontaneous abortion is. Prof. Wigglesworth alluded earlier to this aspect of fetal wastage. Were do you start recording it? One could say clinically recognized abortions. But different institutions will have different ways of recognizing their abortions. I doubt whether this kind of monitoring of the abortion frequency will really be a good warning system as far as malformations or problems occuring. I wonder how one could really come to a reliable monitoring of the fetal wastage regarding the very early occurrences of this problems, where it cannot be clinically recognized. One has indirect figures from hospital records and patients data on parity and gravidity, but I wonder whether that is really the kind of information you are looking for.

**Thomas Pexieder:** There is not so much trouble in definition. You can divide abortions in those happening between the 6th and 8th week, and then between the 8th and 11th week, or you define a period in time. This is your reference point. This would represent for Switzerland for 8–11 week about 3.9% of all pregnancies, which would be about 2000 cases a year. It can certainly be done, and I think the problem of definition can be overcome.

**FP:** *I think these problems of definition are very important. We have also to think of the very important problem with the stillbirth too.*

**Emilio Bossi:** Thinking of your overhead projection and that of Prof. Calame, for me the basic question of today is not there. We would like to have gestational age, neonatal hospitalization, prematurity, etc. But if we want to have teh motivation to do something, we have to ask the question of what it is we want to know. One could be: Organization of neonatal medicine in Switzerland? These sheets are instruments to get data, but we don't have the questions that we want to answer with these instruments. That disturbs me, and I feel a little insecure about it.

**FP:** *I don't want to answer this question, but basically, one of the problems we have in Switzerland, is that we do not have a Ministry of Health saying, for instance, that we have to half our rates of perinatal mortality. Thus we, as professional, have to provide the questions and the goals for the community. We have to accept this kind of idea to go on. One of the points, and it was repeatedly said today, is that we can, with perinatal surveillance epidemiology, decide how to allocate resources. To which group of the population, to which part of Switzerland? Which are the emergent problems, etc.? For this kind of things, epidemiology can provide an answer.*

**Nigel S. Paneth:** Just a comment on data systems in general. The question that Dr. Duc raised at the beginning has been repeated several times, "You have to first know what the question is". It really boils down to the discomfort that academic and scientific people feel with ongoing data collection systems. Why should we let data drive the hypotheses we want to test? Hypothesis should drive the data we collect. It seems to be a backward way of doing science.
There has to be a very special justification for ongoing data collection systems. Essentially, the major justification is universal coverage. It's very hard to make a case for

ongoing data collection systems which are not universal. The history of vital statistics long precedes that of newborn medical care. We have been collecting birth certificates on babies since before intensive care, even since before babies were delivered in hospitals. The legal requirement of the government to record births, is the reason for birth certificates, and all medical information is "piggy-backed" on. But we have learned that this information is very valuable. It enables us to understand the nature and distribution of the problem of infant birth and death. Because vital data are universal and legally required, and because most of the variables of interest are very well categorized, they are very useful. With modest resources we can add one or two key variables, and make the system even more useful.

On the other hand, at times you have specific questions, such as those concerning retrolental fibroplasia, which require a special study in order to understand what's going on. In-between the two poles, we have heard abut data collection efforts which are ongoing but which are not universal, such as the Münsterlingen data base that was described before. These kinds of studies I find much harder to justify. They are intermediate between the special study and the universal ongoing data collection system. The most balanced system consists of an ongoing universal data collection system, to which most of the resurces are devoted, and then special studies, which can be added for special situations. The choice is between examining things universally, but not in great detail, or examining a small number of things, but in great detail. It is the complementarity betwen those two extremes that makes for the best data systems. Perhaps one should avoid that middle area, as one is often trying to do both kinds of study at the same time, which often doesn't work.

**Samuel Pro'hom:** I think that you have today given one good answer to one question, that is, can we stop the increase in the number of low birth weight infants being born? You have shown that by medically assisted fertilization you increase the number of very small infants, and also that there is a large percentage of handicapped children in the survivors. If a medical procedure increases the number of handicapped children which would not be born without us physicians, I think we should stop this procedure. It is now time that we should speak with our colleagues in obstetrics, and suggest that within the next 5 years they should abandon, they should make an embargo, on medically assisted fertilization.

**FP:** *It is not my intention to open a second meeting on this topic. But I could take this opportunity to close the meeting, because it is extremely important to see that what you are proposing is a decision. One of the purposes of health statistics is to provide information to take this kind of decisions. We have seen today that we have a lot of information that needs co-ordinating. We have to design new information systems. You should think, as people working in the perinatal field, that you are lucky because you have a very good event, that is birth. In other fields of epidemiology, it is much more complicated: epidemiology of cancer for instance, because we have no good event to start with. Comparatively, it is easier in this field and we have many possiblities of development.*

*My suggestion is that we stop now and before giving the floor to Prof. Duc, for the closing remarks, I would propose that, with the agreement of Prof. Moessinger, we convene a similar meeting in one year. In the meantime we should have a small multidisciplinary group, trying to work out the proposals developed today, and this group could make a report in one year. One of the first tasks of this group would be to assist Dr. Thomas Spuhler in his efforts to change the birth certificate, and help him cope with the Federal Government.*