

## معقولية إنشاء سجل وطني للعيوب الولادية في سورية: آراء الأطباء

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### الملخص

هدف البحث: كخطوة أولى في تقييم معقولية إنشاء سجل وطني للعيوب الولادية في سورية، تم استقصاء مواقف أطباء الأطفال والمولدين المزاولين للمهنة في سورية تجاه إنشاء مثل هذا السجل.

الطرائق: الدراسة مقطعية عرضية نفذت من خلال إرسال استبيان بريدي يملأ ذاتياً إلى جميع الأطباء المسجلين في الروابط المهنية ذات الصلة في سورية، وهي تحديداً: الجمعية السورية لأطباء الأطفال، والجمعية السورية لأطباء التوليد وأمراض النساء. وبلغ عدد الاستبيانات المرسله 1594 استبياناً.

النتائج: بلغ عدد الاستبيانات الواردة من الأطباء 235 (15.1%) استبياناً فقط، وكان عدد المستجيبين من أطباء الأطفال 110، ومن المولدين 117. عبر جميع المستجيبين تقريباً (97%) عن ضرورة إنشاء هذا السجل، ووصفوا وظائفه وعبروا عن رغبتهم بالإبلاغ عن العيوب الولادية (95.5%).

الاستنتاجات: رغم أن نتائج هذا المسح تقترح اهتماماً بالغاً بضرورة إنشاء هذا السجل والتزاماً بالإبلاغ عن العيوب الولادية بين الأطباء ممن أرسلوا ردودهم، إلا أن نسبة الاستجابة القليلة تجعل الموجودات صعبة التأويل والتعميم، فضلاً عن أنها تقترح ضرورة إنشاء نظام ترصد للعيوب الولادية في سورية من النوع الفاعل. ويبقى التحدي الأكبر في الوصول إلى نظام رصد فعال في سورية.

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## The Feasibility of Establishing a National Birth Defect Registry in Syria: Doctor's Opinions

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### Abstract

**Objective:** As a first step in assessing the feasibility of establishing a national birth defect registry in Syria, we investigated Syrian Paediatricians' and Obstetricians' views and attitudes towards establishing such a registry in the country.

**Methods:** A cross-sectional study, by mailed self-administered questionnaire, was implemented. All physicians registered in the most relevant professional societies, namely the Syrian Paediatrics Association and the Syrian Society for Obstetrics and Gynaecology received the questionnaire. A total of 1594 questionnaires were mailed.

**Results:** A total of 235 questionnaires (15.1%) were returned. Of the respondents, 110 were paediatricians, and 117 were obstetricians. Overall, nearly all respondents (97%) expressed the necessity of establishing the registry. They viewed the functions of the registry and expressed their willingness to notify birth defects (96.5%).

**Conclusions:** Although the results of this survey suggest that there is widespread interest in establishing a national birth defect registry among respondent doctors, and doctors expressed their willingness to notify birth defects to a national registry, the low response rate make the findings hard to interpret and generalize, but also suggest that an active system of surveillance is needed in the Syrian context. Our real challenge is to see this urgently needed registry functioning in the country.

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## **Introduction**

Birth defects are a major cause of stillbirths, infant mortality and childhood morbidity, affecting 2-3% of all babies. Every year an estimated 7.9 million children (6% percent of total births worldwide) are born with a serious birth defect of genetic or partially genetic origin. Additional hundreds of thousands more are born with serious birth defects of post-conception origin, including maternal exposure to environmental agents (teratogens) such as rubella and iodine deficiency. Serious birth defects can be lethal. For those who survive, these disorders can cause lifelong mental and physical disability. The appropriate management of live born infants with significant birth defects constitutes a considerable burden for health care resources [1-2].

The Public Health Model for birth defects is not different from other health problems. It largely consists of interrelationships between monitoring, epidemiological research as well as prevention programmes [3]. The epidemiological approach to birth defects has been the backbone of research into their causes. The etiology of most birth defects is not fully understood. However, some factors are well known. Surveillance of anomalies and creation of local registry is a valuable method for monitoring the impact of preventive measures [4-6].

The improving health indices in some developing countries are indicative of social and economic progress associated with improved health care services and control of infectious diseases and malnutrition. As an expression of this epidemiological transition, the percentage contribution of birth defects and genetic diseases to the infant mortality rate (IMR) is greater in countries where the latter is lowest, reaching 25% in some of the WHO Eastern Mediterranean Region (WHO/EMRO) [7]. Although underestimated, the incidence and prevalence of birth defects were high in most Arab countries including the Gulf region [2, 8-9].

Syria has made great progress in reducing IMR, which decreased from 34.6 per 1000 live births in 1993 [10] to 17.1 per 1000 live births in 2004 [11]. Population-based studies using validated verbal autopsy carried out in Syria in 1996 and 2001 [12-13], have identified the main causes of deaths in childhood. According to the most recent study [13], the main causes of neonatal deaths were birth defects (18.5%), preterm births (23.9%) and birth-related causes (29.4%). These three groups of causes accounted for over 70% of all neonatal deaths. The contribution of birth

defects as a cause of death was as high as 21.7% among infants and 25% among children 1-4 years.

A retrospective record analysis of the six-year period 1992-1997 performed in Damascus Maternity Teaching Hospital, estimated the birth prevalence of birth defects in that hospital at 13.2/1000 live births and stillbirths (95% CI: 12.8-13.6) [14]. The most frequent defects were neural tube defects which accounted for 51.6% of total defects. A statistically significant linear trend of increasing NTDs was noticed between 1992 and 1997. Alongside, a complementary case-control study [15] carried out during the period 1997-1999, showed that the main predictor of birth defects was a history of birth defects in the family (adjusted OR=8.4, 95% CI: 2.3-30.6). The study identified clusters of birth defects and indicated the importance of genetic inheritance.

An effective surveillance system is an important tool to detect trends and birth defect clusters, identify risk factors for birth defects, guide and assess the progress of preventive measures, coordinate with specialized health care and delivery services, and educate the public, as well as advocate to solve this health problem. In our view, the establishment of a National Birth Defect Registry in Syria is extremely important, and thus, as a first step in assessing the feasibility of establishing such a registry, we investigated Syrian Paediatricians' and Obstetricians' views and attitudes towards establishing a National Birth Defect Registry in the country.

#### **Methods**

A cross-sectional survey was carried out through mailing questionnaires to all doctors who are registered with the most related professional societies, i.e., the Syrian Paediatrics Association and the Syrian Society for Obstetricians and Gynaecologists.

The self-administered questionnaire was sent with a covering letter signed by the Chairperson of the Syrian Medical Syndicate to explain the aim of the study and its prospects, and to seek cooperation. The questionnaire consisted mostly of closed questions, including checklists. One open question was added for additional remarks. The questions included basic demographic data for the doctors, a second section about the importance of the registry, its functions and proposed type, and a third section about active involvement of doctors through willingness to notify birth defects and participation in consultative committees.

The survey was mailed to physicians in August 2007, and doctors were asked to send their responses in the enclosed self-addressed and postage-paid envelope within 15 days. No attempt was done to do a second recall, as experience from similar studies in the country showed that there is usually no increase in response rate after the second recall.

A total of 1594 letters were mailed to doctors (655 paediatricians and 939 obstetricians/gynaecologists). A total of 202 addresses out of the 1796 in the original databases shared by the professional societies were not mailed due to their incompleteness and repetitiveness. Another 33 letters were not delivered by the post for reasons related to the change in address inside or outside the country.

Ethical committee approval was not required, since this was an anonymous self-administered questionnaire of health professionals who voluntarily completed the questionnaire. Still the protocol was approved by the Damascus Faculty of Medicine Scientific and Ethical Review Board. All responses were entered into a Microsoft Excel database and analyzed using SPSS for Windows, release 14.0 (SPSS, Inc., Chicago, IL)

### **Results**

We received a total of 235 responses, giving a response rate of 15.1% (235/1561). The response rates among specialist groups varied greatly. We received 110 questionnaires from paediatricians and 117 from Obstetricians, giving a response rate of 17.4% (110/633) and 12.6% (117/928), respectively. Eight physicians did not state their specialty.

Table 1 shows the characteristics of the respondent physicians. In our sample, there were more females than male obstetricians. Most obstetricians worked in private clinics as well as in governmental or public hospitals, as compared to paediatricians who worked more in private clinics only. The mean age of respondent paediatricians was higher than that for obstetricians.

Two hundred physicians (85.8%) felt that birth defects constituted a major public health problem in Syria, while 13 (5.6%) believed it was not a problem at all, and 20 (8.6%) said that they did not know if it was. Table 2 summarizes the findings from the questions concerning physicians' views on the prospects of establishing a National Birth defect Registry. Ninety seven percent of them felt that this is important, and more than half of them thought that the registry should be population-

based using physician notifications, while only 40.4% of them said that it should be hospital-based. The main two functions of the registry as seen by the respondents were determining the types of birth defects and providing epidemiological data to study causation and prevention. Only 43.4% of the physicians envisaged the function of the registry in identifying effective public health interventions. More than 65.1% thought that the Ministry of Health was the best location for such registry. Table 3 demonstrates the findings concerning the doctors' willingness to actively contribute to the suggested registry through notifications or even consultancies. A total of 223 (96.5%) doctors expressed their willingness to notify birth defects. Most of them said that their preferred method of notification is through filling in a notification form. One third of them referred to hospital records as a means of birth defect notification. 12.8% of doctors said that issues related to confidentiality will prevent them from notifying birth defects. When asked if they like to contribute to the registry through being on advisory or consultative committees, ninety four doctors (41.8%) said yes. The main incentive for notifying birth defects as seen by doctors was getting feedback and newsletters/reports. It is of interest to mention that bivariate analysis showed a statistically significantly ( $p=0.03$ ) higher proportion of obstetricians (56.3%) who expressed their willingness to contribute to the advisory committees as compared to paediatricians (37.1%). As for the open question in which we asked doctors to state any additional remarks, three main themes were revealed among the 82 extra remarks communicated by doctors, and they included the followings: the importance of early detection through prenatal diagnosis of birth defects and its implications on the proposed registry, the importance of genetic diseases and the necessity to include this in the registry as to enable research on its causes including environmental ones, and also the importance of defining good means of cooperation and involvement as well as of feedback.

### **Discussion**

In this paper we tried to set the ground for establishing a national birth defect registry in Syria, by starting to assess physicians' attitudes and views towards such registry. Syrian obstetricians and paediatricians who responded to our questionnaire seemed to be very positive about establishing a national birth defect registry. Although nearly all of those who responded felt that this is a priority issue, our response rate was very

low. Explanations for this could well be related to the lack of interest on behalf of the non-respondents, but it could be related to the mailing system in the country which is rather simple and not efficient. Also, studies using similar design in the country have always showed low response rates among doctors [16-17]. Thus our findings might well be subjected to a selection bias. Another limitation of this survey is that we cannot compare the characteristics of those who responded and those who did not. The third important limitation is that one of the outcome variables was measuring intention to notify rather than actual notification, which of course was not possible to assess because the registry is not there yet.

Public health surveillance is the ongoing collection, analysis and interpretation of data essential to the planning, implementation and evaluation of public health interventions [18]. Systematic collection of data on birth defects at population levels is essential to initiating and developing better care and prevention services at all levels. In this study, many Syrian physicians felt that birth defects are a serious public health problem, and some of them correctly enough were not able to tell as to avoid giving an expert opinion in the absence of a surveillance system!. In fact, population-based studies at the country level indicate that over one-fifth of infant mortality is due to birth defects [13]. This estimate is much higher than that noted for Syria in the March of Dimes' global report on birth defects [2]. Genetic factors could well contribute to the high prevalence of birth defects in Syria, due to high rate of consanguinity in the country. According to the Syrian PAPFAM Study [19] which was carried out in 2001, the consanguineous marriages constituted 28.9% of all marriages. Indeed genetic diseases and birth defects are of special importance in the Arab World [20-21]. More than 75% of our doctors felt that provision of genetic data is a core function of the envisaged birth defect registry. They also felt the necessity to determine the main types of birth defects. With the improvement in diagnostic facilities for genetic diseases in the country, this function could also be possible.

The finding that most doctors felt more the relevance of the population-based registry as compared to a hospital-based registry contradicts with the fact that 85% of our sample did not respond. This will implicate that any surveillance system based on passive notifications by doctors would

be of no value. Active Surveillance might well be more relevant in that context although it is labor-intensive [22]. Thus we are planning a pilot project in the country, the evaluation of which should answer such question. In the Syrian context, it seems rather important to have many sources of ascertainment; not only to improve the data quality but also to improve reporting by itself.

More than 95% of the respondents said that they are willing to notify birth defects, largely using a notification form. Yet again, experience in the country with notifiable-by-law communicable diseases showed that notification is not good [16], thus proper planning and follow up seems to be essential for improving notification whether compulsory or not. Issues of confidentiality were of concern to nearly one-sixth of our respondents; although this issue is extremely important, it is for the management of the registry to make sure that all ethical guidelines are reviewed and respected [23].

It is noteworthy to say that our obstetricians were very concerned about the issue of pregnancy termination. The availability of antenatal screening has serious implications for future information collection about birth defects [1, 4, 24- 26].

In Syria, establishing national capacity for surveillance and monitoring of birth defects to inform policy and to allow for more robust evaluation of public health interventions is undoubtedly an asset. Although the results of this survey suggest that there is widespread interest in establishing a National Birth Defect Registry, the low response rate point to the fact that the system needs to be planned properly as to rely more on the active surveillance. Our real challenge is to see such urgently needed registry functioning in the country.

#### **Acknowledgment**

Great appreciations are due to the Syrian Medical Syndicate for his support of the study. The assistance provided by the Syrian Paediatrics Association well as the Syrian Society for Obstetrics and Gynaecology is great. Without their help in providing the addresses, the study would have been impossible. Many thanks for all physicians who responded to our survey. Thanks to all colleagues who commented on this manuscript.



**Tables**

**Table 1: Characteristics of the respondent physicians**

Variable	Paediatricians		Obstetricians /Gynaecologists		All	
	No.	%	No.	%	No.	%
<b>Sex</b>						
<i>Male</i>	78	72.2	81	69.8	159	71
<i>Female</i>	30	27.8	35	30.2	65	29
<b>Place of work *</b>						
<i>Private clinic only</i>	29	26.4	8	6.8	37	16.3
<i>Private clinic + governmental hospitals</i>	19	17.3	5	4.3	24	10.6
<i>Private clinic + private hospitals</i>	22	20	49	41.9	71	31.3
<i>Private clinic + governmental + private hospital</i>	26	23.6	47	40.2	73	32.2
<i>Private clinic + health centre</i>	5	4.5	0	0	5	2.2
<i>Full time governmental job with no private clinic</i>	4	3.6	4	3.4	8	3.5
<i>Others</i>	5	4.5	4	3.4	9	4
<b>Mean age (SD) *</b>	50.3 (10.7)		47 (8.7)		48.6 (9.7)	

\* P < 0.05

**Table 2: Physicians' attitudes and prospects of establishing a National Birth Defect Registry**

Item	No	%
<b>Importance of establishing a national birth defect registry</b>		
<i>Yes</i>	228	97
<i>No</i>	2	0.9
<i>Does not know</i>	5	2.1
<b>Functions of the proposed registry *</b>		
<i>Create a national database</i>	179	76.2
<i>Determine the types of birth defects</i>	205	87.2
<i>Provide statistical data for health services planning</i>	161	68.5
<i>Provide database for interested researchers</i>	155	66
<i>Provide epidemiological data to study causation and prevention</i>	187	79.6
<i>Study the effectiveness of public health interventions</i>	102	43.4
<i>Provide genetic data that is of local and international importance</i>	178	75.7
<i>Other uses</i>	153	65.1
<b>Type proposed registry *</b>		
<i>Population-based using birth certificate</i>	110	46.8
<i>Hospital-based using hospital registries</i>	95	40.4
<i>Population-based using doctors' notification</i>	123	52.3
<b>The most relevant location of the proposed registry *</b>		
<i>Ministry of Health</i>	153	65.1
<i>Syrian Medical Syndicate</i>	38	16.2
<i>Faculty of Medicine/Governmental University</i>	83	35.3
<i>Syrian Paediatric Association</i>	86	36.6
<i>Syrian Society for Obstetrics and Gynaecology</i>	71	30.2
<b>Are you willing to participate in the registry's consultative/advisory committee?</b>		
<i>Yes</i>	102	47.6
<i>No</i>	59	26.2
<i>Has not decided yet</i>	59	26.2

\* Percentages were calculated of all respondents as more than one answer was possible

**Table 3: Physicians' attitudes towards potential notification of birth defects**

Item	No	%
Are you ready to notify a birth defect is you are asked to?		
<i>Yes</i>	223	96.5
<i>No</i>	1	0.4
<i>Has not decided yet</i>	7	3.0
What is the preferred method of notification *		
<i>Use a special form</i>	172	73.2
<i>Notify by phone</i>	66	28.1
<i>Notify by e-mail or the web</i>	52	22.1
<i>Notify through the hospital records</i>	83	35.3
<i>Notify as part of birth certification process</i>	57	24.3
<i>Notify as part of prenatal diagnosis</i>	52	22.1
<i>Notify as part of genetic studies</i>	30	12.8
<i>Notify one type of defects and not all</i>	17	7.2
Do you think that confidentiality issues would prevent from notifying the proposed registry		
<i>Yes</i>	29	12.8
<i>No</i>	181	79.7
<i>Does not know</i>	17	7.5
What incentives do you prefer? *		
<i>Getting feedback and newsletters/reports</i>	192	81.7
<i>Access the data for research purposes</i>	100	42.6
<i>Access the data for scientific meetings/conferences/etc.</i>	75	31.9

\*Percentages were calculated of all respondents as more than one answer was possible

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