Summary of the Prevalence of reported Congenital Birth Defects in 18 Selected Districts in Iraq

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Introduction and Background:

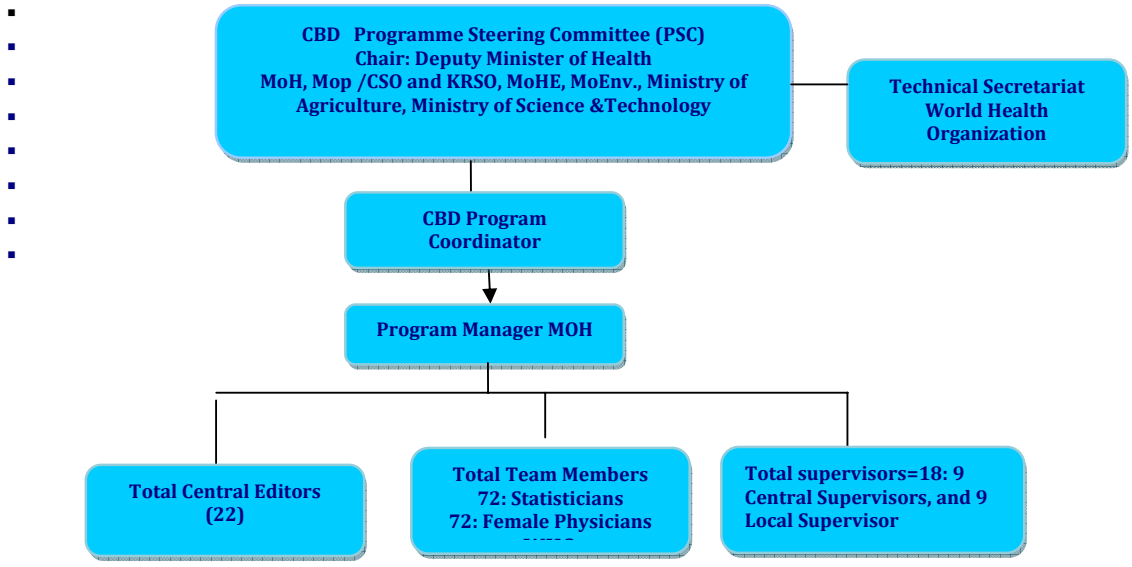
In recent years there have been several anecdotal reports of geographical regions with an unusually high prevalence of congenital birth defects (CBD) in Iraq (1-4). Most of the reports did not meet the norms for an objective study of birth defects, and a review of the published literature could find no clear evidence to support their findings (5). Because of continuing uncertainty the Ministry of Health of Iraq undertook a systematic effort to collect information on the prevalence of congenital birth defects in Iraq. The Ministry designed a household survey in 18 selected districts in Iraq in order to:

1. Assess the magnitude, trend and type of congenital birth defects.
2. Assess the association of congenital birth defects with a limited number of risk factors.
3. Assess the impact on carers for those with congenital birth defects.

This preliminary report focuses primarily on addressing the magnitude, geographical differentials and the trend. The second and third objectives as well as the type of congenital birth defects will be addressed to the extent possible in the full report, which will be made available when the full analysis is completed by the Ministry of Health.

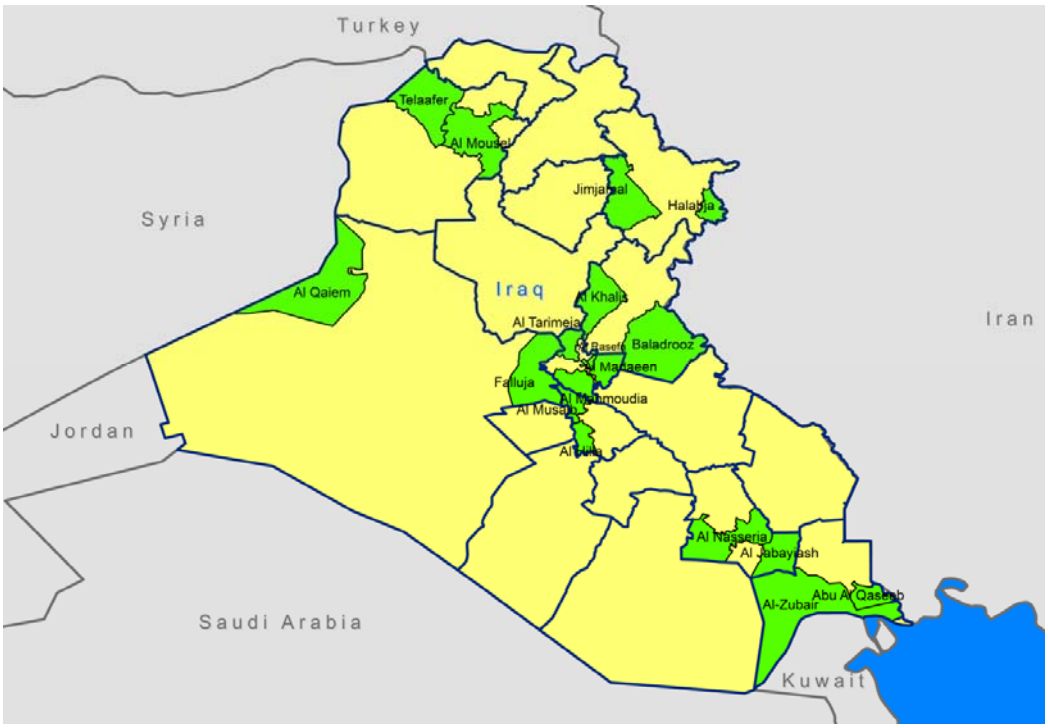
Planning and Implementation structure

Following three planning meetings between the Iraq Ministry of Health and WHO, MOH Iraq established the planning and implementation structure summarised in the Figure below, to design and implement the study. The Steering Committee is headed by a deputy minister and includes public health professionals from MOH, Statistical experts from the Ministry of Planning and experts from the Ministries of Environment, Science and Technology, Higher Education and Agriculture.



Methodology

The survey was conducted between May 2012 and July 2012 in seven governorates of South Centre of Iraq and in September 2012 in one governorate in Kurdistan. Two districts were selected in each governorate, except for Baghdad where there are two health directorates; and two districts were selected from each directorate. The 18 districts included in the study, selected using criteria determined by the Ministry of Health, extended from North to South of the country. They included areas that had and had not been exposed to bombardment or heavy fighting (see map and Table A1).



The survey employed equal sample allocation of 600 households per district, giving a total of 18 x 600 = 10,800 households. A stratified two-stage sample design was used to select households within each district (Qadaa). Subs-districts (Nahia) were stratified by urban and rural, and all districts, except Baghdad/Rasafa, have rural sub-districts. The primary sampling units are clusters (or Census Enumeration areas), and 40 clusters were selected from each district. From each selected cluster 15 households were randomly selected from a household list using simple random sample.

Seventy-two locally recruited teams were trained to conduct the interviews, and each team consisted of four members from Ministry of Health and Ministry of Planning and was headed by a female physician. Standardized training was imparted to the teams on administering questionnaires, and on how to further investigate if a case of CBD was reported.

Three data collection tools were used:[1]

1. A household questionnaire, completed with the head of the household. This collected information on household members including the presence of any CBD, who provides care, household characteristics and detailed information from care providers.
2. A woman questionnaire, completed with all ever-married women in each household aged 15-45 years at the time of the survey. This collected socio-demographic characteristics, a detailed pregnancy history, the outcome of each pregnancy, and family history of any CBD.
3. A detailed questionnaire for each birth with CBD reported by the mother was used to further ascertain the type of CBD and the person who diagnosed or detected it, health care provision during the pregnancy and delivery, any possible exposure to radiation, father's demographic characteristics and parental consanguinity.

The questionnaires were finalised in English, then translated into Arabic and Kurdish. The questionnaires can be accessed via the link included in footnote below. CBD were defined according to the International Classification of Diseases (ICD-10), using 29 codes covering a spectrum of congenital anomalies.

Strengths and limitations:

All studies benefit from their strengths and are constrained by their limitations, and this study is no different.
Strengths are:

- The use of a standardized approach, employing face-to-face interviews in each district.
- The 72 interview teams were professionally qualified and familiar with the district, and each team included medical personnel trained in consistent categorization of the reported congenital birth defects.
- The survey tools were very comprehensive and pilot tested, and the questionnaire was translated into Kurdish for the relevant districts.
- An extensive supervision mechanism was available.

It is also important to recognize the limitations of this study, including:

- The study relies on the memories of the persons who were interviewed and their self reporting of specific events that may have occurred several years in the past, which is less reliable than prospective data collection supported by medical certification. In particular, medical records were available for only 32% of total reported congenital birth defects. There was no mechanism to ascertain CBD outside of the maternal reporting process.
- The reliability of self reported information can also be compromised by difficulty in recalling events accurately after many years. For example, women

[1] The topics and the questions covered in each questionnaire can be downloaded from the Ministry of Health http://www.moh.gov.iq and WHO website http://www.emro.who.int/irq/iraq-infocus/iraq-congenital-birth-defect.html

were asked to remember details of spontaneous abortions, stillbirths and births with congenital birth defects from over 15 years ago. Accurate recollection over several years has been proven to be difficult in similar surveys and possibility of recall error must be taken into account when interpreting results. In general, recalled information on early pregnancy termination (abortion) is less reliable than recall of events during late pregnancy and delivery (e.g. still birth), which in turn is less complete than reporting of deaths after delivery.

Because of the limitations mentioned above, prevalence estimated in this study cannot be compared directly with data from congenital anomaly registries in high income settings, where diagnosis is made by specialists using strict criteria and advanced diagnostic techniques. In addition, very few comparable studies have been reported in the literature. Therefore the data are best analyzed using intra-country comparisons or comparing with estimates from other countries in the region.

Findings

Out of 10,800 visited households, 10,355 (95.9%) completed the household questionnaire. The reason most often documented for no response was no one was present at the home at the time of the survey. The mean household size was 6.8, ranging from 4.7 in Halabja to 8.9 in Al Qaim. Nearly, all identified ever-married women of reproductive age 15-49 years old 10,745 (99.1%) completed the woman questionnaire, and reported on 43,387 pregnancies. At the time of the survey 12% of ever pregnant women were currently pregnant, and mean numbers of pregnancies and pregnancy losses were 4.3 and 0.7, respectively.

The prevalence of congenital birth defects among living household members, as reported by the head of the household, was 13.8 per 1,000. Overall prevalence among all births reported by the mothers was 21.7 per 1,000 births. Around a quarter (27.5%) of the congenital birth defects were diagnosed by parents, and 70% were reported to have been diagnosed by health providers (doctors, nurses or birth attendants). The interviewers were able to view medical records for 58.5% of these cases which corresponds with 32% of the total. Medical records were more often available for the more recent births, but harder to find for the older events.

Trends in pregnancy outcomes

Table 1 gives the trends in, spontaneous abortion, stillbirth and congenital birth defects per 1,000 pregnancies/births with (95%CI), relative to the survey date. The reported spontaneous abortion rate is within the expected range (11-22%) for the most recent period, but on the low side for periods at least 5 years ago (6). The apparent increase over time is commonly observed in surveys and likely due to underreporting for earlier periods: women are less accurate in their reports of early pregnancy endings that occurred longer ago.

The reported stillbirth rate for 2008-2012 is considerably lower than the WHO estimate of 32/1,000 (7). This suggests that possible underreporting of stillbirths, or

that stillbirth rates in Iraq are lower than estimated elsewhere. In terms of trend there is no significant increase or decrease in the last two decades.

Congenital birth defects were reported for 23.7 per 1,000 births in the most recent period. This is within the range of the 20-40/1,000 depending on inclusion criteria and ascertainment methods reported from high income countries (8). There is no trend in reported congenital birth defects during the last 15 years (1998-2012), as the three five-year periods have very similar rates. The rates of congenital birth defects before 1998 are somewhat lower, especially before 1993, but are very likely to suffer from reporting bias given the long recall period.

Table 1: Trends in reported spontaneous abortion, stillbirths and congenital birth defects rates, per 1,000 pregnancies/births

Years before the survey*	Approximate year of birth	Total pregnancies	Spontaneous abortion /1,000 pregnancies		Stillbirth /1,000 births		Congenital birth defect /1,000 births	
			Mean	*(95% CI s)*	Mean	*(95%CI s)*	/1,000 births	*(95%CI s)*
0-4	2008-2012	12,314	116.3	*(108.2-124.4)*	11.8	*(8.8-14.8)*	23.7	*(19.9-27.6)*
5-9	2003-2007	10,759	85.3	*(76.8-93.9)*	14.5	*(10.4-18.7)*	26.2	*(21.5-30.9)*
10-14	1998-2002	8,618	84.0	*(73.9-94.1)*	10.6	*(6.7-14.6)*	23.6	*(19.3-28.0)*
15-19	1993-1997	6,081	67.7	*(58.4-77.0)*	16.3	*(8.8-23.7)*	15.3	*(10.7-19.9)*
20-24	1988-1992	3266	67.4	*(49.9-84.9)*	8.7	*(3.7-13.7)*	7.6	*(3.8-11.4)*
Total	1988-2012	43,387	**94.1**	***(89.5-98.7)***	**14.4**	***(12.2-16.7)***	**21.7**	***(19.1-24.2)***

Note: birth is defined as either stillbirth or live birth with gestational age 7+ months.
*Time period is truncated at 25 years before the survey, and the total is for the entire period.

Pregnancy outcomes by Districts

Table 2 presents results by district. There is considerable variation by district in all three outcomes, but wide confidence intervals indicate that much of the variation may be random. Highest prevalence of congenital birth defects (over 30/1,000) was reported from Al Qaim (Anbar) and Halabja (Sulaimaniyah) while Jimjamal (Sulaimaniyah), Al Nasseria (Thi Qar) and Fallujah (Anbar) report prevalence below 15/1,000. There is no clear relationship between stillbirths and birth defects (see scatter plot below).

Table 2: Rates of spontaneous abortion, stillbirth, and congenital birth defects per 1000 /pregnancies/births, by districts

Governorate	District	Total pregnancies	Spontaneous abortion /1,000 pregnancies		Stillbirths /1,000 births		Congenital birth defects /1,000 births	
			Mean	*95%CI*	Mean	*95%CI*	Mean	*95%CI*
Nineveh	Al Mousel	2,768	103.8	*(91.2-116.4)*	15.6	*(9.3-21.9)*	22.1	*(15.0-29.2)*
Nineveh	Telaafer	2,585	56.5	*(43.9-69.1)*	12.8	*(7.1-18.6)*	18.5	*(12.5-24.5)*
Sulaimaniyah	Halabja	1,570	116.3	*(99.9-132.7)*	27.1	*(20.3-33.9)*	34.5	*(23.5-45.5)*
Sulaimaniyah	Jimjamal	1,946	123.0	*(95.4-150.6)*	24.0	*(16.1-31.9)*	9.1	*(3.4-14.8)*
Diyala	Al Khalis	1,991	89.1	*(68.1-110.1)*	10.3	*(4.8-15.7*	20.7	*(14.2-27.3)*
Diyala	Baladrooz	2,064	69.7	*(51.7-87.7)*	14.0	*(7.2-20.7)*	18.1	*(11.6-24.6)*
Anbar	Fallujah	1,815	35.8	*(19.5-52.0)*	9.9	*(0.8-18.9)*	14.6	*(8.0-21.2)*
Anbar	Al Qaim	2,974	80.6	*(68.2-93.0)*	12.7	*(5.2-20.3)*	39.7	*(26.1-53.3)*
Baghdad/Rasafa	Al Rasefa	2,403	102.7	*(91.0-114.4)*	21.2	*(13.3-29.2)*	25.4	*(16.9-34.0)*
Baghdad/Rasafa	Al Madaeen	2,396	86.1	*(67.2-105.1)*	9.8	*(5.8-13.8)*	20.3	*(12.6-27.9)*
Baghdad/ Karch	Al Mahmoudia	2,001	69.1	*(54.2-83.9)*	8.0	*(4.4-11.6)*	23.6	*(16.4-30.7)*
Baghdad/ Karch	Al Tarimeia	2,399	96.9	*(80.5-113.3)*	12.0	*(5.8-18.1)*	26.4	*(18.2-34.6)*
Babil	Al Hilla	2,499	134.3	*(119.0-149.7)*	16.4	*(11.0-21.9)*	25.8	*(18.2-33.5)*
Babil	Al Musaib	2,390	94.4	*(82.1-106.6)*	11.0	*(6.6-15.5)*	26.0	*(18.0-34.0)*
Thi Qar	Al Nasseria	2,822	102.2	*(82.2-122.1)*	7.8	*(4.0-11.6)*	14.1	*(9.0-19.2)*
Thi Qar	Al Jabayiash	3,557	87.3	*(76.1-98.5)*	14.6	*(9.2-19.9)*	15.5	*(10.2-20.7)*
Basrah	Abu Al Qaseeb	2,653	85.0	*(71.8-98.2)*	15.3	*(9.4-21.1)*	16.9	*(11.6-22.2)*
Basrah	Al Zubair	2,554	46.8	*(34.0-59.6)*	5.5	*(1.2-9.8)*	15.0	*(9.8-20.1)*
	Total	**43,387**	**94.1**	***(89.5-98.7)***	**14.4**	***(12.2-16.7)***	**21.7**	***(19.1-24.2)***

Note: birth is defined as either stillbirth or live birth with gestational age 7+ months.

Conclusion

The survey data was collected by interviewing women of reproductive age in a sample of households in 18 selected districts of Iraq. The rates for spontaneous abortion, stillbirths and congenital birth defects found in the study are consistent with or even lower than international estimates. The study provides no clear evidence to suggest an unusually high rate of congenital birth defects in Iraq. However, the results do reflect local variation as well as a lower rate of congenital birth defects before 1998. Although this may be attributable to difficulties in recalling events that occurred in the more distant past, further in/depth analysis of available data and additional information is needed to confirm this and explain the local variations.

Consultations:

In order to obtain wider scientific input into the analysis and interpretation of the preliminary results, and for the sake of transparency, two important processes were employed.

1. In June 2013 an expert meeting was conducted at WHO Geneva. Participants included the Deputy Minister of Health of Iraq and technical staff in the Public Health Directorate, and WHO experts from Headquarters, the Eastern Mediterranean Regional Office and the WHO Iraq Country Office participated and extensively deliberated on the results and agreed strategic actions on moving forward.

2. An expert peer review meeting was held at WHO on 27 to 28 July 2013. The expert group comprised experts from London School of Hygiene and Tropical Medicine (Professor Joy Lawn and Professor Simon Cousens), Fafo Research Foundation Norway (Manager Director Dr Jon Pedersen) WHO Collaborating Centre for Community Control of Hereditary Disorders, University College London (Professor Bernadette Modell), and the United States Centers for Disease Control and Prevention (Dr Owen Devine and Dr Cynthia A. Moore). These experts have scientific insight into the global issues of CBD, and for two days the initial results and the discussion of the June meeting were taken into account. The experts also suggested future approaches for detailed analysis of the very large body of data acquired during the study.

Next steps/ Recommendations:

This report contains information from preliminary analysis of the data. Given the amount of data gathered in this survey, analysis and interpretation by the Ministry of Health will continue to make use of the collected data, and a detailed analysis will be published in a full report.

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Table A1

Governorates	**District**	
Ninawa	Telaafer	AL-Mousel
Sulaimaniyah	Halabja	Jimjamal
Diyala	Al Khalis	Baladrooz
Anbar	Fallujah	Al Qaim
Baghdad/Rasafa	Al- Madaeen	Al Rasefa
Baghdad/ Karch	Al Mahmoudia	Al Tarimeia
Babil	AL-Musaib	Al-Hilla
Theeqar	Al Jabayiash	Al Nasseria
Basrah	Al Zubair	Abu Al Qaseeb

Plot A1: of CBD against stillbirth (Correlation coefficient=0.218 p-value=0.39)