East Midlands & South Yorkshire
Congenital Anomalies Register
One of The Infant Mortality & Morbidity Studies

TIMMS

Congenital Anomalies in Births

2005 to 2009

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Background information

- **Time period covered:** These tables summarise congenital anomalies reported in pregnancies which ended between January 1st 2005 and December 31st 2009 inclusive in the East Midlands and South Yorkshire (EMSYCAR) region.

- **EMSYCAR Geography:** In 2006, the geography of the area covered by EMSYCAR changed substantially for a second time. The 39 Primary Care Trusts, (PCTS) which had formed three separate Strategic Health Authorities (SHAs) and part of a fourth, and had constituted the EMSYCAR area since 2002, were re-organised. Six of the original 39 remained unchanged; the rest were reformed into nine larger PCTs.

    - The data presented here follows the boundaries of the fourteen 'new' PCTs and one CTP (Care Trust Plus) which postdate October 2006. Data for 2005 has been allocated to the relevant 'new' PCT.

- **Regional Coverage:** At the present time (April 2011) all but one PCT provides funding support to EMSYCAR. Data for the five year period from 2005-9 consequently appears here for fourteen PCTs only.

    - Between 2005 and 2009, the Register attempted to continue data collection throughout its whole area, despite the lack of funding from some PCTs, in order not to compromise data quality for those PCTs which remained. Available data has therefore been backdated in this present report to cover the 'missing' years for the PCTs which have subsequently rejoined the register's activities.

    - Relevant data, for clinical use or audit purposes, is available, upon request, to clinicians in all units which have continued to supply data to EMSYCAR.

- **Surveillance:** No Congenital Anomaly data was sent to the National Congenital Anomaly System (NCAS) for PCTs which withdrew funding support from the Register, and no surveillance of these areas was undertaken, either at regional or national level, between 2005 and 2009. NCAS previously divided its published data between areas covered by Congenital Anomaly Registers, where reported rates are much higher and more accurate (and which includes those PCTs reported separately here) and areas of England which are not covered by registers (including the non-contributing PCTs in the EMSYCAR region.)

    - NCAS discontinued all routine anomaly surveillance from the end of 2008. EMSYCAR is now the only resource available to perform this essential public health function for its resident population. Computer software provided through membership of the European Surveillance Network (EUROCAT) is employed for those PCTs contributing to EMSYCAR, and every effort is made to submit current data into the EUROCAT system as it becomes available (i.e. one year in advance of the required schedule), in order for surveillance to be as timely as possible.

- **Routine surveillance and monitoring cannot be undertaken for any PCT that has withdrawn funding from EMSYCAR.**

- The BINOCAR Registers have responded to the closure of NCAS by establishing, in co-operation with EUROCAT, a data hub for England and Wales, which will comprise aggregated data from the English and Welsh Regional Registers and is due to start operation in 2011. For further details, please see the following section of this Report.

- **'Minor' Anomalies** The BINOCAR Registers have continued to refine the list of 'minor' anomalies for exclusion, to bring it into closer alignment with the EUROCAT list. The same working group has also addressed the issue of coding variability, both between different regional Registers, and between regional Registers and NCAS. All Registers have now adopted an agreed BINOCAR coding framework, which NCAS also used for births between January 1st 2007 and December 31st 2008. Some variation in reported anomaly rates in certain subgroups (particularly musculoskeletal and endocrine & metabolic disorders) is therefore to be expected in data from 2007 onwards.

- **Table Format:** In preparing the tables presented here, anomaly rates (expressed as a ratio per 10,000 births) have been preferred to exact numbers. Individual PCTs are, of course, welcome to contact EMSYCAR to request greater detail for their own area. This will be provided wherever possible, although it should be noted that, according to national guidelines, the number of anomaly cases in any given cell should always exceed a minimum of five in order that data confidentiality is not compromised and that there is no possibility of individual cases being identified. For small areas and/or rare anomalies, this criterion may frequently not be met.

- **Further Information:** A more detailed background to EMSYCAR and its data collection methods may be found in previous Reports available from EMSYCAR, Dept. of Health Sciences, University of Leicester, 22-28 Princess Road West, Leicester, LE1 6TP, or by e-mailing timms@leicester.ac.uk with a request.

Establishment of the BINOCAR Data Hub

- Following extensive consultation, agreement has recently been secured with EUROCAT to permit the establishment of a **BINOCAR Data Hub**. Funding has been obtained from the Health Quality Improvement Partnership (HQIP) for a year in the first instance.

- The BINOCAR data hub will be based on the EUROCAT model, and will utilise modified software to include an expanded set of variables, reflecting the need not only for surveillance, but also the ability to provide relevant data to the NHS Fetal Anomaly Screening Programme, for audit and evaluation purposes.

- The Data Hub will be co-ordinated by a small team based within the National Down Cytogenetic Register in the Wolfson Institute of Preventive Medicine at Barts and the London School of Medicine and Dentistry. All BINOCAR Regional Registers in England and Wales will continue to contribute anonymised data to EUROCAT, at the same time sending copies of their data, together with the additional variables relating to screening and antenatal diagnosis, to the hub.

- Each Register will continue to remain responsible for its own data, and will be required to issue permission each time its data is used.

- It is intended that the BINOCAR Hub will go some way to filling the gap left by the demise of the National Congenital Anomaly System (NCAS), which had collected data on Congenital Anomalies in England and Wales since the aftermath of the thalidomide tragedy until its closure at the end of 2008. Whilst data coverage will not be national for England the data will be of very high quality.

- For more information, please consult the BINOCAR website, which will post relevant details as they become available throughout 2011: www.binocar.org

EMSYCAR Data Summary

- The **total number of births** occurring in the EMSYCAR region **has been rising steadily** since 2001. Initially, this was due to the entry of Northamptonshire into EMSYCAR in 2002-3, but since then the birth rate continued to increase until 2009, when a slight decrease was observed.

- In any given year, **about 2.4% of all births in the EMSYCAR region have serious, reportable anomalies**. Slightly more males (2.6%) than females (1.9%) and more multiple (around 3%) than singleton (2.4%) births are affected. These well-recognised trends are again confirmed by the data presented here.

- Despite reduced funding during the period, the number of cases **reported to the European Surveillance System, EUROCAT, has increased steadily to over 1500.** This reflects the huge amount of work, both by the EMSYCAR team and notifiers in the many maternity units, devoted to tracking cases and obtaining outcome data.

- However, **there is evidence of a slight fall in the number of cases reported to EMSYCAR, particularly in the postnatal period**, over the last few years. Whilst the proportion of antenatally notified cases that are successfully followed to delivery and diagnosis has increased, and the number lost to follow-up has been reduced to a minimum, the absolute number of reported cases has declined. Renewed efforts are being made to encourage notifications from the neonatal units and paediatricians throughout the region, together with attempts to find alternative methods of notification to replace those lost as a result of reorganisation within individual PCTs.

- While anomaly rates have historically varied between PCTs, Table 5 demonstrates that the **rates for individual anomalies have largely remained stable for EMSYCAR as a whole.** Comparison with rates reported elsewhere in Europe can easily be made from the EUROCAT website (**www.eurocat-network.eu**)

- An exception lies within the cardiovascular group of anomalies, where efforts to secure data from the Regional Paediatric Cardiac Centre at Glenfield Hospital, Leicester resulted in success during 2008, and surgical and cardiology notifications were backdated for the cohort of children born in the EMSYCAR region since 1997.

- Initially **an overall rise of approximately 20% in the notified rates of cardiac anomalies** resulted. However, it has not so far been possible to obtain data from Glenfield for 2009 or 2010. Consequently, rates of cardiac anomalies in the EMSYCAR region remain apparently lower than elsewhere in Europe. Improving the reporting of postnatally diagnosed cardiac anomalies remains a priority for EMSYCAR.

Ongoing EMSYCAR Activities

- **Audit and research activities** have continued using Register data. EMSYCAR has joined several European-wide research initiatives, and a number of collaborative papers have been published using EMSYCAR data.[1][2][3][4][5][6]

- EMSYCAR contributes to a number of UK projects. Publications include the monitoring and prenatal detection of structural fetal congenital anomalies in England and Wales; [7] an audit of congenital diaphragmatic hernia, and an investigation into the antenatal diagnosis of **schizencephaly** is awaiting publication. EMSYCAR has also contributed to a **BINOCAR audit of Down syndrome** cases between 2003 and 2006 and continues to participate with an investigation into the **rising incidence of gastroschisis.**

- EMSYCAR-led research projects include an investigation of the appropriateness of treatment regimes for cases of **sexual differentiation** reported to the Register over a ten year period, and outcomes from antenatally detected cases of **AVSD.** An investigation has begun into all cases of Turner syndrome reported to the Register, together with an associated review of all the reported cases of cystic hygroma, an update of a paper published by the Leicester team in 2005.[9]

- Recent EMSYCAR data has been used by the **National Fetal Anomaly Screening Programme** in a review of antenatal diagnosis rates for selected congenital anomalies. Data has been utilised by the Paediatric Stoma Nurses Group UK, to update their supporting literature.[10] Data from EMSYCAR, and other BINOCAR Registers, has also been utilised by the National Perinatal Epidemiology Unit in Oxford to validate data obtained from BAPS-CASS (the British Association of Paediatric Surgeons Congenital Anomalies Surveillance System). This has attempted to evaluate the success of the BAPS-CASS data collection methods.

- Other requests for data from the Register from local clinicians continue to be dealt with as appropriate. Regular data matching and cleaning is undertaken in conjunction with the North Trent Clinical Genetics Service, the National Down Syndrome Cytogenetic Register, together with local ultrasound, antenatal and fetal medicine units, mainly with a view to establishing antenatal detection rates. Training sessions have continued to be provided at the request of local clinicians.

- Professor Elizabeth Draper continues in her role as Chair of the British Isles Network of Congenital Anomaly Registers (BINOCAR). Dr Judith Budd continues as a member of the EUROCAT Coding Issues Group and BINOCAR Coding Committee. EMSYCAR was represented at the EUROCAT Annual Register Leaders' Meetings in Bilbao and Dublin in 2009 and 2010.

- Research using EMSYCAR data has been accepted for presentation at the Perinatal Medicine 2011 meeting at Harrogate in June, and at the 14th International Medical Geography Symposium to be held in Durham, UK, in July 2011. Data will also be presented to the Society of Perinatal Epidemiological Research (SPER), and the Society for Epidemiologic Research (SER) in Montreal in June 2011, and the 11th EUROCAT Scientific Conference in Antwerp, also in June 2011.

1. Garne E, Khoshnood B, Loane M, Boyd PA, Dolk H (2010), "Termination of Pregnancy for Fetal Anomaly After 23 Weeks of Gestation: A European Register-Based Study", *BJOG*, Vol 117, No 6, pp 660-666.

2. Boyd P, Loane M, Garne E, Khoshnood B, Dolk H and a EUROCAT Working Group (2011), "Sex Chromosome Trisomies in Europe: Prevalence, Prenatal Detection and outcome of Pregnancy", *European Journal of Human Genetics*, Vol 19, pp 231-234 [doi: 10.1038/ejhg.2010.148]

3. Barisic I, Tokic V, Loane M, Bianchi F, Calzolari E, Garne E, Wellesley D, Dolk H and EUROCAT Working Group (2008), "Descriptive Epidemiology of Cornelia de Lange Syndrome in Europe", *American Journal of Medical Genetics Part A*, Vol 146A, pp 51-59.

4. Loane M, Dolk H, Bradbury and a EUROCAT Working Group (2007), "Increasing Prevalence of Gastroschisis in Europe 1980-2002: A Phenomenon Restricted to Younger Mothers?" *Paediatric and Perinatal Epidemiology*, Vol 21, pp 363-369.

5. Abramsky L, Dolk H and a EUROCAT Folic Acid Working Group (2007), "Should Europe Fortify a Staple Food with Folic Acid?" *The Lancet*, Vol 369, pp 641-642.

6. Prevalence of Neural Tube Defects (NTD) in younger mothers in Europe 2000-2008; analysis of the EUROCAT database (2010) Report to Bayer Schering Pharma

7. Boyd PA, Tonks AM, Rankin J, Rounding C, Wellesley D, Draper E and the BINOCAR working group. "Monitoring the prenatal detection of structural fetal congenital anomalies in England and Wales: register based study. *J. Med Screen 2011; 18(1): 2-7.*

8 Wright J., Budd J., Field D., & Draper E (2010), "Epidemiology and outcome of congenital diaphragmatic hernia: a nine year experience" *Paediatric and Perinatal Epidemiology* Vol 25, pp 144-149

9. Howarth E., Draper E., Budd J., Konje J., Clarke M., & Kurinczuk J (2005) Population-based study of the outcome following the prenatal diagnosis of cystic hygroma *Prenatal Diagnosis* vol 25, pp 286-291

10. Paediatric Stoma Nurse Group (2010) A Guide to Stoma Care and Related Conditions in Childhood. ConvaTec Inc.

Anomaly Clusters and Trends

- For the great majority of anomalies, trends have remained stable or show a slight decrease between 2005 and 2009, reflecting the time lag necessary for the more recently diagnosed anomalies to reach the Register. **A few anomalies, however, appear to be increasing, such as spina bifida, exomphalos and, in particular, renal dysplasia**. These trends appear to be consistent with those appearing in other BINOCAR register areas, though they will be kept under review.

- There has also been **some local concern over cases of skeletal dysplasia** reported from PCTs which unfortunately were not funding surveillance of their population by EMSYCAR during the relevant years.

- Routine surveillance of EMSYCAR data by EUROCAT highlighted **several potential clusters in time** during the years 2003-2007.

- These were all investigated by EMSYCAR, with the following outcomes:

    - **32 cases of hydrocephalus in the period September 2006 – January 2007**. One duplicate case had already been removed from the EMSYCAR database but not updated with EUROCAT. The suspected cluster therefore resolved.

    - **8 cases of common arterial truncus in the period August 2005 – January 2006**. As above.

    - **8 cases of transposition of the great arteries between January 2006 and February 2006.** Correct gestational ages of deliveries known to EMSYCAR had not been backdated with EUROCAT, which had used estimations. Once the appropriate amendments had been made, the suspected cluster resolved.

    - **5 cases of co-arctation between April and May 2006.** As for TGA.

    - **14 cases of VSD in the period December 2005 – January 2007**. As for TGA.

    - **7 cases of hypospadias in January 2008.** As for TGA.

    - **18 cases of renal dysplasia in October and November 2007.** Although updated data caused the identified cluster to resolve, a rising trend was also apparent in EMSYCAR data throughout the time period under review. The reasons may lie in a combination of better data reporting since EMSYCAR began, and much improved follow up of antenatally reported cases. The overall EMSYCAR rates remain below the EUROCAT mean, and below the rates reported by other UK Registers. However, rising rates could also represent a real increase in the incidence of this group of anomalies. This matter is under active review.

- **8 cases of cleft palate in May 2005.**

    - All cases were verified
    - 5 occurred in close proximity around Town A. 2 others were in very close proximity in Town B (50 miles away). 1 further case occurred elsewhere in the EMSYCAR region.
    - Information provided by the local data notifiers indicated that the 2 cases in Town B were both known drug and alcohol abusers.
    - There was no such history for the other cases.
    - Local contacts believed that no local concerns were raised by the media, general public or health professionals.
    - There was no evidence of other or similar clusters elsewhere in the EMSYCAR region.

Regrettably, it was not possible to pursue any further investigations over this potential cluster since 7 of the 8 cases occurred in PCTs which had chosen to withdraw from EMSYCAR, and **the excess of observed over expected cases in this time period therefore remains unexplained**.

- EMSYCAR investigated four anomalies displaying increased trends over the 2003 – 2007 period, which were identified by EUROCAT surveillance software. These were **hypoplastic left heart syndrome, congenital cystic adenomatoid malformation, gastroschisis and renal dysplasia (mentioned above).**

    - **In the cases of hypoplastic left heart syndrome and CCAM, the increased trend is believed to be artefactual**, as a result of cases occurring in earlier years not being notified to EMSYCAR in time for inclusion in the appropriate year's dataset to EUROCAT.

    - The **increasing trend demonstrated by gastroschisis** is real and already recognised by other BINOCAR Registries. A number of projects are in progress to investigate possible explanations.

    - The **increasing trend displayed in the case of renal dysplasia** may also be real, though it is more likely to be the result of improved reporting. This argument is supported by the fact that the increase is much more apparent in the southern and northern areas of the region where efforts to secure better follow-up of antenatally reported cases has been concentrated.

The Fetal Anomaly Screening Programme and the Antenatal Detection of Congenital Anomalies

In January 2010 the NHS Fetal Anomaly Screening Programme (FASP) published a set of National Standards and Guidance for the 18^{+0} to 20^{+6} Fetal Anomaly Scan in England.

This document determined a set of **eleven conditions**, each capable of being detected antenatally, considered 'important, being fatal, associated with morbidity or requiring immediate postnatal support'. From April 2010, these conditions are to be screened for and audited by ultrasound departments. Target antenatal detection rates vary, but all exceed 50%.

They are as follows:

Condition	Target Detection Rate %
Anencephaly	98
Open Spina Bifida	90
Cleft Lip	75
Diaphragmatic Hernia	60
Gastroschisis	98
Exomphalos	80
Serious Cardiac Anomalies	50
Bilateral Renal Agenesis	84
Lethal Skeletal Dysplasia	60
Edwards Syndrome (Trisomy 18)	95
Patau Syndrome (Trisomy 13)	95

Along with other BINOCAR Registers, EMSYCAR supplied data to FASP during the consultation process. This section of the current Report attempts to assess how many of the targets would have been achieved, had they been in existence, within the EMSYCAR Region from 2005-2009, in order to provide a context for monitoring activities from 2010 onwards.

A number of difficulties became apparent during this exercise, and the solutions which have been developed, are explained below.

1. **While some of the anomalies identified by FASP were well defined from the beginning, others – particularly 'serious cardiac anomalies' and 'lethal skeletal dysplasia' were not.**

    i. EUROCAT established a new subgroup for the surveillance of **Serious Cardiac Anomalies** in the autumn of 2010. In the absence of any definition offered by FASP at this time, BINOCAR Registers adopted the EUROCAT definition, at least as an interim measure, and this has been used in the present Report. This decision will be reviewed if FASP subsequently offer a definition of what they believe to constitute 'a serious cardiac anomaly'.

ii. **Serious Cardiac Anomalies** referred to in this Report therefore encompass the following thirteen conditions:

Condition	ICD-10
Common Truncus	Q200
Transposition of the Great Arteries	Q203
Double Inlet Ventricle/Common Ventricle	Q204
AVSD	Q212
Fallot's Tetralogy	Q213
Pulmonary Valve Atresia	Q220
Tricuspid Atresia/Stenosis	Q224
Ebstein's Anomaly	Q225
Hypoplastic Right Heart Syndrome	Q226
Aortic Valve Atresia/Stenosis	Q230
Hypoplastic Left Heart Syndrome	Q234
Coarctation of the Aorta	Q251-Q2519
Total Anomalous Pulmonary Venous Drainage (TAPVD)	Q262

iii. **Lethal skeletal dysplasias** are a difficult group of anomalies to define. Postnatal investigations are almost always necessary before an exact diagnosis can be reached. Antenatal Reporting is therefore very difficult, and is, of itself, of limited accuracy.

Some of the current FASP literature appears to include osteogenesis imperfecta; the precise subtype(s) have not been specified, and some types of OI are not lethal.

EMSYCAR, along with all other Registers affiliated to EUROCAT, uses the WHO ICD-10 classification system to code reported anomalies. There is no facility within ICD-10 to distinguish between different types of OI, which all code Q780 and therefore potentially lethal cases cannot be identified.

For present purposes the definition of skeletal dysplasia, therefore, has been limited to thanatophoric dysplasia (Q771)and short-rib/Jeune's syndrome (Q772) only. While both are acknowledged to be lethal, this narrow definition will exclude some other equally lethal but less well-described conditions. This problem will be discussed centrally by BINOCAR and the definition reviewed if necessary.

2. **There are always difficulties associated with allocating anomaly cases to individual hospitals**, particularly so with the more serious anomalies discussed here. In addition, smaller units, which refer problem cases to larger centres, have been tempted to leave the reporting of such cases to the Tertiary Centre. EMSYCAR therefore cannot always allocate these cases to their 'correct' originating unit, and may even remain unaware that the cases were, in fact, suspected antenatally.

i. Since this is the first time EMSYCAR has published Antenatal Diagnosis Tables, due to the difficulties of attributing cases to individual hospitals, antenatal diagnosis tables are presented by the PCT of mother's residence at delivery. As such n**o inferences should be drawn from the following tables concerning the relative performance of individual hospital units or hospital trusts.** However, it is clear that mothers living in some areas appear more likely to have their baby's anomalies identified antenatally than mothers living elsewhere, and more work is needed to address this issue.

ii. The decision to base EMSYCAR's reporting of antenatal diagnoses around the PCT of mother's residence will be reviewed in the light of any future NHS reorganisation.

3. **There may be many different reasons for an apparently 'late' diagnosis**, apart from the implication that an anomaly has been 'missed' during routine antenatal care, including:

    - Mothers who book too late for screening
    - Mothers who transfer into an area in the later stages of a pregnancy
    - Mothers who decline antenatal screening
    - Mothers who decline invasive testing

    i. Anomalies are rare and affect a relatively small proportion of total live and stillbirths. Few individual anomalies occur within any one PCT and this one pregnancy can have wide repercussions on the achievement, or not, of a specific target. Even within a large PCT, 19 successfully antenatally diagnosed anencephaly cases, where the target rate is 98%, could appear to be compromised by the one (5%) that is missed until delivery because the mother declines a fetal anomaly scan.

4. It is also often the case that **although the pregnancy may be diagnosed antenatally with a problem, the precise nature of the anomaly does not become known until much later**, or even postnatally.

    i. Where this is obvious from the notifications sent to EMSYCAR, a pragmatic view has been taken and the main anomaly under review has been assumed to be antenatally diagnosed.

    ii. However, for example, a case of cleft lip, or AVSD diagnosed antenatally does not always mean that the underlying cause of Trisomy 13 or 21 was also so recognised, and some of the chromosomal antenatal diagnosis rates shown here may be slightly inflated as a result. Conversely, an antenatal notification of Trisomy 21 that fails to mention a known AVSD would lead to an apparently lower antenatal diagnosis rate of cardiac anomalies in that PCT/Unit. **It is therefore vital that notifiers report ALL antenatally diagnosed or suspected anomalies to EMSYCAR, particularly where these involve, or might involve, anomalies on the FASP list.**

Table AN1: Fetal Anomaly Screening Programme (FASP) Targets for Antenatal Detection of Congenital Anomalies

	FASP Target % Antenatal Detection Rate	EMSYCAR Region % Antenatal Detection Rate 2005-2009
Anencephaly	98	95.8
Open Spina Bifida	90	92.1
Cleft Lip	75	69.3
Diaphragmatic Hernia	60	83.5
Gastroschisis	98	94.1
Exomphalos	80	87.2
Serious Cardiac Anomalies	50	55.8
Bilateral Renal Agenesis	84	85.5
Lethal Skeletal Dysplasia*	60	100
Edwards syndrome - Trisomy 18	95	87.0
Patau syndrome - Trisomy 13	95	89.4

Table AN2: FASP Targets: Results by PCTs 2005-2009

	Barnsley	Bassetlaw	Derby City	Derbyshire County	Doncaster
Anencephaly					
Open Spina Bifida					
Cleft Lip					
Diaphragmatic Hernia					
Gastroschisis					
Exomphalos					
Serious Cardiac					
Bilateral Renal Agenesis					
Lethal Skeletal Dysplasia*					
Edwards syndrome/Trisomy 18					
Patau syndrome/Trisomy 13					

	Leicester City	Leicestershire County & Rutland	Lincolnshire	North East Lincolnshire	North Lincolnshire
Anencephaly			#		
Open Spina Bifida			#		
Cleft Lip			#		
Diaphragmatic Hernia			#		
Gastroschisis			#		
Exomphalos			#		
Serious Cardiac			#		
Bilateral Renal Agenesis			#		
Lethal Skeletal Dysplasia*			#		
Edwards syndrome/Trisomy 18			#		
Patau syndrome/Trisomy 13			#		

	Northampton-shire	Nottingham City	Nottingham-shire County	Rotherham	Sheffield
Anencephaly					
Open Spina Bifida					
Cleft Lip					
Diaphragmatic Hernia					
Gastroschisis					
Exomphalos					
Serious Cardiac					
Bilateral Renal Agenesis					
Lethal Skeletal Dysplasia*					
Edwards syndrome/Trisomy 18					
Patau syndrome/Trisomy 13					

*Lethal Skeletal Dysplasia = Thanatophoric Dysplasia and Short Rib/Jeune's Syndrome only

Key:

	100% cases antenatally diagnosed
	Met/exceeded target
	Missed target
	No cases recorded
#	No data presented

Table 1: Number and proportion of births with one (or more) confirmed congenital anomaly, by year of birth 2000 – 2009

Year	Total Births	Births with one or more confirmed, probable or suspected anomaly		Births with one or more confirmed or probable anomaly		Births with multiple confirmed or probable anomalies	
		n	%	n	%	n	%
2000	55,541	1,757	3.2	1,576	2.8	411	0.7
2001	54,302	1,851	3.4	1,711	3.2	396	0.7
2002	54,601	1,829	3.3	1,735	3.2	378	0.7
2003	64,307	1,802	2.8	1,620	2.5	355	0.6
2004	66,346	1,708	2.6	1,590	2.4	384	0.6
2005	67,318	1,649	2.4	1,618	2.4	365	0.6
2006	70,153	1,766	2.5	1,731	2.5	409	0.6
2007	72,549	1,658	2.3	1,627	2.2	402	0.6
2008	74,469	1,550	2.1	1,501	2.0	383	0.5
2009	74,101	1,412	1.9	1,371	1.9	363	0.5

Table 2: Number and proportion of births with one (or more) confirmed congenital anomaly, by plurality and year of birth 2000 – 2009

Year	Total Births	Singletons	Multiples	Singleton births - one or more anomaly		Multiple births - one or more anomaly	
				n	%	n	%
2000	55,541	53,947	1,594	1,516	2.8	47	2.9
2001	54,302	52,818	1,484	1,658	3.1	51	3.4
2002	54,601	52,874	1,727	1,666	3.2	69	4.0
2003	64,307	62,518	1,789	1,570	2.5	50	2.8
2004	66,346	64,446	1,900	1,551	2.4	39	2.1
2005	67,318	65,401	1,917	1,492	2.3	58	3.0
2006	70,153	68,018	2,135	1,659	2.4	53	2.5
2007	72,549	70,507	2,042	1,553	2.2	69	3.4
2008	74,469	72,284	2,185	1,399	1.9	67	3.1
2009	74,101	71,713	2,388	1,305	1.8	66	2.8

***** Proportion of cases of unknown plurality under 0.1% per annum

Table 3: Number and proportion of births with one (or more) confirmed congenital anomaly, by infant sex and year of birth 2000 - 2009

Year	Total Births	Males	Females	Males with one or more anomaly		Females with one or more anomaly	
				n	%	n	%
2000	55,541	28,340	27,201	880	3.1	619	2.3
2001	54,302	28,026	26,276	951	3.4	692	2.6
2002	54,601	28,070	26,531	972	3.5	707	2.7
2003	64,307	32,941	31,366	870	2.6	658	2.1
2004	66,346	34,163	32,183	887	2.6	596	1.9
2005	67,318	34,509	32,809	885	2.6	616	1.9
2006	70,153	35,848	34,305	953	2.6	679	2.0
2007	72,549	37,273	35,276	907	2.4	572	1.6
2008	74,469	38,211	36,258	803	2.1	558	1.5
2009	74,101	37,973	36,128	718	1.9	522	1.4

***** Proportion of cases of unknown sex varies between 0.1% and 0.2% per annum

Table 4: Birth status of cases reported to EMSYCAR with one (or more) confirmed congenital anomaly, by year of delivery 2005 – 2009

	Cases with confirmed/probable anomalies	TOP		Fetal Loss <=23+6 wks		Stillbirth >=24+0 wks		Alive		Died	
		n	%	n	%	n	%	n	%	n	%
2005	1,618	325	20.1	41	2.5	30	1.9	1147	70.9	75	4.6
2006	1,731	326	18.8	32	1.8	44	2.5	1231	71.1	98	5.7
2007	1,627	300	18.4	28	1.7	25	1.5	1182	72.6	92	5.7
2008	1,501	307	20.5	42	2.8	27	1.8	1071	71.4	54	3.6
2009	1,371	286	20.9	40	2.9	40	2.9	950	69.3	55	4.0
TOTAL	**7,848**	**1,544**	**19.7**	**183**	**2.3**	**166**	**2.1**	**5,581**	**71.1**	**374**	**4.8**

Table 5: Number and rates of selected congenital anomalies and congenital anomaly groups per 10,000 total births, by year of birth* * or end of pregnancy in cases of spontaneous loss or termination

Complete EMSYCAR Area	Total Births	67318	70153	72549	74469	74101	340673
	ICD-10	2005	2006	2007	2008	2009	TOTAL
CENTRAL NERVOUS SYSTEM	Q000-Q079	181	156	175	153	155	**820**
		27.0	*22.2*	*24.1*	*20.5*	*20.9*	*22.9 (21.4, 24.5)*
All Neural Tube Defects	Q000-Q019	94	84	83	77	79	**417**
	& Q050-Q059	*14.0*	*12.0*	*11.4*	*10.3*	*10.7*	*11.6 (10.5, 12.8)*
Anencephaly	Q000-Q002	51	40	35	31	33	**190**
		7.6	*5.7*	*4.8*	*4.2*	*4.5*	*5.3 (4.6, 6.1)*
Encephalocele	Q010-Q019	10	11	12	10	7	**50**
		1.5	*1.6*	*1.7*	*1.3*	*0.9*	*1.4 (1.0, 1.8)*
Spina Bifida	Q050-Q059	35	34	41	40	42	**192**
		5.2	*4.8*	*5.7*	*5.4*	*5.7*	*5.4 (4.6, 6.1)*
Isolated Hydrocephalus	Q030-Q039	30	34	60	42	48	**214**
		4.5	*4.8*	*8.3*	*5.6*	*6.5*	*6.0 (5.2, 6.8)*
Microcephaly	Q020	9	5	7	*	8	**
		1.3	*0.7*	*1.0*	*	*1.1*	*0.9 (0.6, 1.3)*
Eye anomalies	Q100-Q159	15	10	11	12	7	**55**
		2.2	*1.4*	*1.5*	*1.6*	*0.9*	*1.5 (1.2, 2.0)*
CARDIOVASCULAR SYSTEM	Q200-Q269	337	405	372	306	269	**1689**
		50.1	*57.9*	*51.3*	*41.1*	*36.3*	*47.1 (44.9, 49.4)*
Serious Cardiac Anomalies	Q20-Q26 various*	133	147	128	109	114	**631**
		19.8	*21.0*	*17.6*	*14.6*	*15.4*	*18.5 (16.2, 19.0)*
Ventricular septal defect	Q210	106	133	124	114	79	**556**
		15.7	*19.0*	*17.1*	*15.3*	*10.7*	*15.5 (14.2, 16.8)*

	ICD-10	2005	2006	2007	2008	2009	TOTAL
CARDIOVASCULAR SYSTEM (cont'd)							
Atrial septal defect	Q211	92	90	84	71	**60**	**397**
		13.7	*12.8*	*11.6*	*9.5*	*8.1*	*11.1 (10.0, 12.2)*
Atrio-ventricular septal defect	Q212	15	19	30	19	22	**105**
		2.2	*2.7*	*4.1*	*2.6*	*3.0*	*2.9 (2.4, 3.5)*
Fallot's Tetralogy	Q213	24	18	23	29	15	**109**
		3.6	*2.6*	*3.2*	*3.9*	*2.0*	*3.0 (2.5, 3.7)*
Transposition of the great vessels	Q203	25	22	20	21	29	**117**
		3.7	*3.1*	*2.8*	*2.8*	*3.9*	*3.3 (2.7, 3.9)*
Hypoplastic left heart syndrome	Q234	26	35	26	13	21	**121**
		3.9	*5.1*	*3.6*	*1.7*	*2.8*	*3.4 (2.8, 4.1)*
Coarctation of the aorta	Q251	20	26	19	18	14	**97**
		3.1	*3.7*	*2.6*	*2.4*	*1.9*	*2.7 (2.2, 3.3)*
Patent Ductus Arteriosus(>=37 wks gest)	Q250	22	53	55	34	21	**185**
		3.3	*7.6*	*7.6*	*4.6*	*2.8*	*5.2 (4.4, 6.0)*
UROGENITAL SYSTEM	Q500-Q649	331	366	365	327	269	**1658**
		49.2	*52.2*	*50.4*	*43.9*	*36.3*	*46.3 (44.1, 48.5)*
Renal agenesis and hypoplasia	Q600-Q609	19	30	41	28	25	**143**
		2.8	*4.3*	*5.7*	*3.8*	*3.4*	*4.0 (3.4, 4.7)*
Bladder/urethral anomalies	Q640-Q649	29	25	25	36	19	**134**
		4.3	*3.6*	*3.4*	*4.8*	*2.6*	*3.7 (3.1, 4.4)*
Cystic kidneys	Q610-Q619	41	37	45	63	40	**226**
		6.1	*5.3*	*6.2*	*8.5*	*5.4*	*6.3 (5.5, 7.2)*
Hypospadias and congenital chordee	Q540-Q549	117	126	133	98	90	**564**
		17.4	*18.0*	*18.3*	*13.2*	*12.1*	*15.7 (14.5, 17.1)*
Hydronephrosis	Q620	95	113	106	90	77	**481**
		14.1	*16.1*	*14.6*	*12.1*	*10.4*	*13.4 (12.2, 14.7)*

	ICD-10	2005	2006	2007	2008	2009	TOTAL
GASTRO-INTESTINAL SYSTEM	Q350-Q459	173	195	174	181	158	**881**
		25.7	*27.8*	*24.0*	*24.3*	*21.3*	*24.6 (23.0, 26.2)*
All clefts	Q350-Q379	103	104	98	113	83	**501**
		15.3	*14.8*	*13.5*	*15.2*	*11.2*	*14.0 (12.8, 15.3)*
Cleft palate only	Q35	37	31	29	38	30	**165**
		5.5	*4.4*	*4.0*	*5.1*	*4.0*	*4.6 (3.9, 5.4)*
Cleft lip only	Q36	20	24	25	25	12	**106**
		3.0	*3.4*	*3.4*	*3.4*	*1.6*	*3.0 (2.4, 3.6)*
Cleft lip & palate	Q37	46	49	44	50	41	**230**
		6.8	*7.0*	*6.1*	*6.7*	*5.5*	*6.4 (5.6, 7.3)*
Atresia/stenosis small intestine	Q410-Q419	10	22	16	12	15	**75**
		1.5	*3.1*	*2.2*	*1.6*	*2.0*	*2.1 (1.6, 2.6)*
Atresia/stenosis large intestine	Q420-Q429	17	26	18	25	19	**105**
		2.5	*3.7*	*2.5*	*3.4*	*2.6*	*2.9 (2.4, 3.5)*
Other intestine	Q430-Q439	23	25	14	20	20	**102**
		3.4	*3.6*	*1.9*	*2.7*	*2.7*	*2.8 (2.3, 3.5)*
Tracheo-Oesophageal fistula	Q390-Q393	17	22	18	13	17	**87**
		2.5	*3.1*	*2.5*	*1.7*	*2.3*	*2.4 (1.9, 3.0)*
MUSCULOSKELETAL SYSTEM	Q650-Q799, Q180-Q189, Q380-Q389	364	445	435	426	398	**2068**
		54.1	*63.4*	*60.0*	*57.2*	*53.7*	*57.7 (55.2, 60.2)*
Limb reductions	Q710-Q739	49	60	49	43	42	**243**
		7.3	*8.6*	*6.8*	*5.8*	*5.37*	*6.8 (5.9, 7.7)*
Polydactyly	Q690-Q699	77	74	68	70	82	**371**
		11.4	*10.5*	*9.4*	*9.4*	*11.1*	*10.3 (9.3, 11.5)*
Syndactyly	Q700-Q709	56	48	48	38	45	**235**
		8.3	*6.8*	*6.6*	*5.1*	*6.1*	*6.6 (5.7, 7.4)*
All Talipes (incl.postural)	Q660-Q669	136	124	123	129	102	**614**
		20.2	*17.7*	*17.0*	*17.3*	*13.8*	*17.1 (15.8, 8.5)*

	ICD-10	2005	2006	2007	2008	2009	TOTAL
MUSCULOSKELETAL SYSTEM (cont'd)							
Congenital Diaphragmatic Hernia	Q790	25	24	19	22	19	**109**
		3.7	*3.4*	*2.6*	*3.0*	*2.6*	*3.0 (2.5, 3.7)*
Gastroschisis	Q793	33	43	35	41	34	**186**
		4.9	*6.1*	*4.8*	*5.5*	*4.6*	*5.2 (4.5, 6.0)*
Exomphalos	Q792	25	31	34	34	32	**156**
		3.7	*4.4*	*4.7*	*4.6*	*4.3*	*4.4 (3.7, 5.1)*
RESPIRATORY SYSTEM	Q300-Q349	22	26	28	14	33	**123**
		3.3	*3.7*	*3.9*	*1.96*	*4.5*	*3.4 (2.8, 4.1)*
CHROMOSOMAL ANOMALIES	Q900-Q999	288	258	221	261	261	**1259**
		42.8	*36.8*	*30.5*	*35.0*	*31.2*	*35.1 (33.2, 37.1)*
Trisomy 21*	Q900-Q909	155	132	114	144	123	**668**
		23.0	*18.8*	*15.7*	*19.3*	*16.6*	*18.6 (17.2, 20.1)*
Trisomy 18*	Q910-Q913	34	37	27	42	37	**177**
		5.1	*5.3*	*3.7*	*5.6*	*5.0*	*4.9 (4.2, 5.7)*
Trisomy 13*	Q914-Q917	14	20	19	15	17	**85**
		2.1	*2.0*	*2.6*	*2.0*	*2.3*	*2.4 (1.9, 2.9)*
Turner's Syndrome*	Q960-Q969	22	17	12	26	21	**98**
		3.3	*2.4*	*1.7*	*3.5*	*2.8*	*2.7 (2.2, 3.3)*
All other chromosomes (excluding * above)	Q920-Q959 & Q970-Q999	64	52	50	34	34	**234**
		9.5	*7.4*	*6.9*	*4.6*	*4.6*	*6.5 (5.7, 7.40*
SYNDROMES AFFECTING MULTIPLE SYSTEMS	Q870-Q879	27	29	27	14	15	**112**
		4.0	*4.1*	*3.7*	*1.9*	*2.0*	*3.1 (2.6, 3.8)*

	ICD-10	2005	2006	2007	2008	2009	TOTAL
SKIN & INTEGUMENT	Q800 - Q849	8	10	11	11	*	**
		1.2	*1.4*	*1.5*	*1.5*	*0.5*	*1.2 (0.8, 1.6)*
OTHER ANOMALIES							
Isolated Cystic Hygroma	D1810	14	8	22	16	9	**69**
		2.1	*1.1*	*3.0*	*2.1*	*1.2*	*1.9 (1.5, 2.4)*
Other Cystic Hygroma	D1810 + other	27	34	30	34	49	**174**
		4.0	*4.8*	*4.1*	*4.6*	*6.6*	*4.9 (4.2, 5.6)*
Other anomalies	Q851-Q859; Q890-Q899; D550; D573	18	23	22	7	12	**82**
		2.7	*3.3*	*3.0*	*0.9*	*1.6*	*2.3 (1.8, 2.8)*

*** fewer than 5 per cell**

**** total withheld to preclude identification of fewer than 5 per cell**

Table 6: Anomalies by Birth Status 2005 – 2009

	TOP %	Fetal Loss %	Stillbirth %	Livebirth %
All EMSYCAR cases	**19.7**	**2.3**	**2.1**	**75.9**
All Neural Tube Defects	**76.0**	**2.2**	**2.4**	**19.5**
Anencephaly	84.2	2.6	2.6	10.5
Encephalocele	70.0	4.0	4.0	22.0
Spina Bifida	69.1	1.6	1.6	27.7
All Cardiovascular	**13.2**	**1.4**	**2.7**	**82.7**
Serious Cardiac	20.1	1.3	3.8	74.8
VSD	9.4	0.7	1.8	88.1
ASD (excl. PFO)	5.7	1.1	0.6	92.5
TGA	8.5	0.0	1.7	89.7
Hypoplastic left heart	40.2	0.8	4.1	54.9
Tetralogy of Fallot	12.8	2.8	1.8	82.6
AVSD	20.0	1.0	7.6	71.4
Co-arctation	3.1	2.1	1.0	93.8
All Respiratory	**13.9**	**2.5**	**3.3**	**80.3**
CCAM	5.8	1.9	1.9	90.4
All Gastro-intestinal	**10.1**	**1.2**	**2.3**	**86.4**
TOF +/- OA	8.0	0.0	2.3	89.7
Cleft Palate	2.4	0.0	1.2	96.4
Cleft Lip	17.9	0.0	3.8	78.3
Cleft Lip & Palate	16.5	1.7	1.3	80.4

Table 6 cont'd.

	TOP %	Fetal Loss %	Stillbirth %	Livebirth %
All Urogenital	**8.3**	**1.3**	**1.6**	**88.8**
Renal Agenesis	41.3	2.8	4.9	51.0
Cystic Kidneys	17.3	0.9	2.7	79.2
Hydronephrosis	2.1	0.6	0.4	96.9
All Musculoskeletal	**15.4**	**2.4**	**2.5**	**79.7**
Limb Reductions	25.1	2.5	3.7	68.7
Diaphragmatic Hernia	22.0	1.8	5.5	70.6
Gastroschisis	6.5	3.8	2.2	87.6
Exomphalos	50.6	13.5	3.2	32.7
All Syndromes	**19.6**	**3.6**	**6.3**	**70.5**
All Chromosome	**51.3**	**5.2**	**3.2**	**40.3**
Trisomy 21	47.9	3.1	1.6	47.3
Trisomy 18	74.6	5.1	6.2	14.1
Trisomy 13	71.8	8.2	4.7	15.3
45X	59.2	17.3	2.0	21.4

Table 7: Anomalies by Maternal Age 2005 – 2009

Maternal Age	<20 %	20-24 %	25-29 %	30-34 %	35-39 %	>40 %	% Age not known*
All Births EMSYCAR area	**8.0**	**21.6**	**27.3**	**25.7**	**14.4**	**3.1**	**0.0**
All EMSYCAR cases	**8.5**	**20.2**	**24.6**	**23.6**	**16.0**	**5.9**	**1.3**
All CNS Anomalies	**13.2**	**27.2**	**14.3**	**24.7**	**16.0**	**4.0**	**0.6**
All Neural Tube Defects	10.6	24.3	25.2	22.4	13.9	3.1	0.5
Anencephaly	11.6	25.3	21.6	22.6	15.3	3.2	0.5
Encephalocele	8.0	18.0	44.0	16.0	6.0	8.0	0.0
Spina Bifida	11.0	24.6	25.1	22.0	14.1	2.6	0.5
All Cardiovascular	**6.9**	**18.2**	**25.0**	**24.0**	**16.3**	**4.9**	**4.7**
Serious Cardiac	8.7	15.2	25.4	26.3	15.4	5.2	3.8
VSD	6.1	18.7	25.0	24.8	16.4	6.5	2.5
ASD (excl. PFO)	7.5	19.0	25.9	19.0	12.6	5.2	10.9
TGA	11.1	14.5	25.6	28.2	11.1	4.3	5.1
HLH	10.7	19.0	29.8	24.0	14.0	2.5	0.0
Tetralogy of Fallot	7.3	15.6	27.5	25.7	16.5	4.6	2.8
AVSD	8.6	13.3	24.8	21.0	22.9	9.5	0.0
Co-arctation	7.2	18.6	15.5	32.0	12.4	7.2	7.2
All Respiratory	**6.6**	**22.1**	**32.0**	**25.4**	**11.5**	**2.5**	**0.0**
CCAM	11.5	26.9	32.7	19.2	7.7	1.9	0.0
All Gastro-Intestinal	**8.3**	**20.9**	**27.4**	**25.8**	**12.7**	**4.8**	**0.2**
TOF +/- OA	3.4	10.3	32.2	31.0	13.8	8.0	1.1
Cleft Palate	3.6	20.6	30.3	31.5	12.1	1.8	0.0
Cleft Lip	6.6	21.7	25.5	26.4	14.2	5.7	0.0
Cleft Lip + Palate	10.4	24.3	27.8	23.5	9.6	4.3	0.0

Table 7 cont'd.

Maternal Age	<20 %	20-24 %	25-29 %	30-34 %	35-39 %	>40 %	% Age not known
All Urogenital	**8.4**	**22.9**	**26.9**	**24.5**	**14.3**	**2.9**	**0.1**
Renal Agenesis	14.8	24.6	23.9	22.5	11.3	2.8	0.0
Cystic kidneys	8.8	25.7	27.0	24.3	12.8	2.2	0.0
Hydronephrosis	9.6	21.6	25.4	24.9	15.4	3.1	0.0
All Musculoskeletal	**10.9**	**21.1**	**26.4**	**23.1**	**14.5**	**4.0**	**0.1**
Limb Reductions	11.5	18.1	30.5	24.7	11.1	4.1	0.0
Diaphragmatic Hernia	7.3	14.7	31.2	22.0	22.0	2.8	0.0
Gastroschisis	14.6	50.4	21.1	10.6	1.6	1.6	0.0
Exomphalos	7.7	14.7	19.9	23.1	23.1	11.5	0.0
All Syndromes	**4.5**	**25.0**	**25.9**	**21.4**	**18.8**	**2.7**	**1.8**
All Chromosome	**4.5**	**10.3**	**14.3**	**20.7**	**29.6**	**19.5**	**1.1**
Trisomy 21	2.8	7.5	11.4	17.5	36.2	23.7	0.9
Trisomy 18	4.5	10.2	11.3	20.3	26.6	26.6	0.6
Trisomy 13	2.4	7.1	14.1	27.1	31.8	17.6	0.0
45X	16.3	20.4	18.4	25.5	15.3	3.1	1.0

***** The % of cases with unknown maternal age is higher among those anomaly groups which tend to be diagnosed later in the neonatal or post-neonatal period and/or where paediatrics/paediatric surgery is the only or chief source of anomaly notification

Table 8: Barnsley PCT: Rates* of selected anomaly groups 2005 – 2009

* Per 10,000 births

Barnsley	ICD-10 Code	2005	2006	2007	2008	2009	TOTAL 95% Confidence intervals
Central Nervous System	Q000 – Q079	47.7	10.9	36.1	39.4	10.6	28.5 (20.3; 39.0)
Eye, ear	Q100 – Q179	4.0	0.0	0.0	0.0	0.0	0.7 (0.02; 4.1)
Cardiovascular	Q200 – Q269	23.8	29.0	21.7	21.5	24.7	24.1 (16.6; 33.9)
Serious Cardiac	Q20 various	15.9	18.1	7.2	10.8	14.1	13.2 (7.8; 20.8)
Urogenital	Q500 – Q649	27.8	36.2	21.7	39.4	14.1	27.8 (19.7; 38.1)
Gastro-intestinal	Q350 – Q459	23.8	25.4	25.3	28.7	21.1	24.9 (17.2; 34.7)
Musculo-skeletal	Q180 – Q189 Q380 – Q389 Q650 – Q799	55.6	47.1	65.1	52.8	49.3	54.1 (42.5; 67.9)
Respiratory	Q300 – Q349	4.0	0.0	0.0	0.0	0.0	2.9 (0.8; 7.5)
Chromosomal	Q900 – Q999	31.8	25.4	21.7	43.0	17.6	27.8 (20.0; 38.1)
Syndromes	Q870 – Q879	0.0	0.0	3.6	0.0	0.0	0.7 (0.02; 4.1)

Table 9: Bassetlaw PCT: Rates* of selected anomaly groups 2005 – 2009

* Per 10,000 births

Bassetlaw	ICD-10 Code	2005	2006	2007	2008	2009	TOTAL 95% Confidence Intervals
Central Nervous System	Q000 – Q079	17.8	51.4	16.0	24.9	25.2	26.9 (15.4; 43.8)
Eye, ear	Q100 – Q179	0.0	0.0	0.0	0.0	0.0	0.0
Cardiovascular	Q200 – Q269	8.9	34.3	8.0	58.0	0.0	21.9 (11.7; 37.4)
Serious Cardiac	Q20 various	0.0	17.1	0.0	24.9	0.0	8.4 (2.7; 19.6)
Urogenital	Q500 – Q649	35.6	25.7	8.0	8.3	8.4	16.8 (8.1; 30.1)
Gastro-intestinal	Q350 – Q459	26.7	17.1	63.8	49.8	33.6	38.7 (24.6; 58.1)
Musculo-skeletal	Q180 – Q189 Q380 – Q389 Q650 – Q799	35.6	51.4	39.9	33.2	50.4	42.1 (27.2; 62.1)
Respiratory	Q300 – Q349	0.0	0.0	0.0	8.3	0.0	1.7 (0.00; 9.4)
Chromosomal	Q900 – Q999	8.9	25.7	31.9	58.0	42.0	33.7 (20.6; 52.0)
Syndromes	Q870 – Q879	0.0	0.0	8.0	8.3	0.0	3.4 (0.4; 12.2)

Table 10: Derby City PCT: Rates* of selected anomaly groups 2005 - 2009

* Per 10,000 births

Derby City	ICD-10 Code	2005	2006	2007	2008	2009	TOTAL 95% Confidence Intervals
Central Nervous System	Q000 – Q079	19.9	18.2	17.9	2.7	16.7	14.8 (9.6; 21.9)
Eye, ear	Q100 –Q179	3.3	0.0	0.0	0.0	0.0	0.6 (0.01; 3.3)
Cardiovascular	Q200 – Q269	36.6	63.9	53.7	33.0	27.8	42.6 (33.4; 53.7)
Serious Cardiac	Q20 various	10.0	30.4	23.9	8.2	11.1	16.6 (11.0; 24.0)
Urogenital	Q500 – Q649	73.1	88.2	41.8	52.2	33.4	56.8 (46.0; 69.4)
Gastro-intestinal	Q350 – Q459	33.2	21.3	20.9	27.5	22.2	24.9 (17.9; 33.6)
Musculo-skeletal	Q180 – Q189 Q380 – Q389 Q650 – Q799	46.5	100.4	56.7	68.7	55.6	65.7 (54.1; 79.2)
Respiratory	Q300 – Q349	0.0	6.1	6.0	0.0	2.8	3.0 (1.0; 6.9)
Chromosomal	Q900 – Q999	26.6	21.3	17.9	43.9	22.2	26.6 (19.4; 35.7)
Syndromes	Q870 – Q879	3.3	6.1	0.0	2.7	2.8	3.0 (1.0; 6.9)

Table 11: Derbyshire County PCT: Rates* of selected anomaly groups 2005 - 2009

* Per 10,000 births

Derbyshire County	ICD-10 Code	2005	2006	2007	2008	2009	TOTAL 95% Confidence Intervals
Central Nervous System	Q000 – Q079	23.9	15.7	18.1	18.9	15.5	18.4 (14.4; 23.2)
Eye, ear	Q100 –Q179	2.7	0.0	1.3	1.3	2.6	1.6 (0.6; 3.4)
Cardiovascular	Q200 – Q269	38.5	40.7	36.1	25.1	20.7	3.1 (26.7; 38.2)
Serious Cardiac	Q20 various	22.5	24.9	18.1	7.5	7.7	16.1 (12.3; 20.6)
Urogenital	Q500 – Q649	37.1	40.7	38.7	18.9	27.1	32.4 (26.9; 38.6)
Gastro-intestinal	Q350 – Q459	22.5	24.9	15.5	21.4	19.4	20.7 (16.4; 25.8)
Musculo-skeletal	Q180 – Q189 Q380 – Q389 Q650 – Q799	45.1	55.1	40.0	39.0	37.4	43.2 (36.9; 50.3)
Respiratory	Q300 – Q349	2.7	0.0	0.0	0.0	6.5	1.8 (0.7; 3.7)
Chromosomal	Q900 – Q999	53.1	26.2	28.4	27.7	28.4	32.6 (27.2; 38.9)
Syndromes	Q870 – Q879	0.0	3.9	1.3	1.3	1.3	1.6 (0.6; 3.4)

Table 12: Doncaster PCT: Rates* of selected anomaly groups 2005 – 2009

* Per 10,000 births

Doncaster	ICD-10 Code	2005	2006	2007	2008	2009	TOTAL 95% Confidence Intervals
Central Nervous System	Q000 – Q079	19.6	30.3	27.0	28.8	28.5	26.9 (20.0; 35.5)
Eye, ear	Q100 –Q179	0.0	0.0	0.0	0.0	0.0	0.0
Cardiovascular	Q200 – Q269	16.8	30.3	16.2	23.5	15.5	20.5 (14.5; 28.1)
Serious Cardiac	Q20 various	5.6	16.5	8.1	13.1	5.2	9.7 (5.7; 15.3)
Urogenital	Q500 – Q649	36.4	46.9	37.9	47.1	28.5	39.3 (30.8; 49.4)
Gastro-intestinal	Q350 – Q459	30.8	66.2	35.2	23.5	25.9	36.1 (27.9; 45.8)
Musculo-skeletal	Q180 – Q189 Q380 – Q389 Q650 – Q799	50.4	66.2	54.1	62.7	57.0	58.1 (47.7; 70.2)
Respiratory	Q300 – Q349	2.8	2.8	0.0	2.6	0.0	1.6 (0.3; 4.7)
Chromosomal	Q900 – Q999	16.8	24.8	16.2	54.9	25.9	28.0 (20.9; 36.7)
Syndromes	Q870 – Q879	2.8	0.0	2.7	0.0	2.6	1.6 (0.3; 4.7)

Table 13: Leicester City PCT: Rates* of selected anomaly groups 2005 – 2009

* Per 10,000 births

Leicester City	ICD-10 Code	2005	2006	2007	2008	2009	TOTAL 95% Confidence Intervals
Central Nervous System	Q000 – Q079	28.1	29.2	35.5	34.5	24.8	30.5 (24.0; 38.1)
Eye, ear	Q100 –Q179	6.5	0.0	5.9	5.8	3.8	4.4 (2.2; 7.9)
Cardiovascular	Q200 – Q269	97.2	58.5	63.2	46.0	45.7	61.3 (52.0; 7.2)
Serious Cardiac	Q20 various	32.4	14.6	27.6	21.1	15.2	22.0 (16.6; 28.7)
Urogenital	Q500 – Q649	69.1	112.7	80.9	82.5	95.3	88.2 (76.9; 100.6)
Gastro-intestinal	Q350 – Q459	32.4	20.9	27.6	42.2	24.8	29.7 (3.3; 37.2)
Musculo-skeletal	Q180 – Q189 Q380 – Q389 Q650 – Q799	82.1	114.8	67.1	63.3	89.6	83.0 (72.1; 95.1)
Respiratory	Q300 – Q349	10.8	4.2	2.0	1.9	5.7	4.8 (2.5; 8.4)
Chromosomal	Q900 – Q999	69.1	39.7	43.4	42.2	34.3	45.3 (37.3; 54.4)
Syndromes	Q870 – Q879	8.6	4.2	0.0	5.8	3.8	4.4 (2.2; 7.9)

Table 14: Leicestershire County & Rutland PCT: Rates* of selected anomaly groups 2005 – 2009 * Per 10,000 births

Leicestershire County & Rutland	ICD-10 Code	2005	2006	2007	2008	2009	TOTAL 95% Confidence Intervals
Central Nervous System	Q000 – Q079	21.3	24.0	20.8	23.5	36.1	25.1 (20.2; 30.9)
Eye, ear	Q100 –Q179	4.3	5.6	4.2	1.4	0.0	3.1 (1.5; 5.5)
Cardiovascular	Q200 – Q269	55.4	71.9	47.1	33.2	31.9	47.8 (10.9; 55.5)
Serious Cardiac	Q20 various	22.7	24.0	20.8	15.2	12.5	19.0 (14.8; 24.1)
Urogenital	Q500 – Q649	81.0	73.3	81.6	54.0	40.2	65.9 (57.8; 74.9)
Gastro-intestinal	Q350 – Q459	31.3	28.2	36.0	24.9	19.4	27.9 (22.7; 40.0)
Musculo-skeletal	Q180 – Q189 Q380 – Q389 Q650 – Q799	56.8	59.2	77.5	62.3	58.3	62.9 (54.9; 71.6)
Respiratory	Q300 – Q349	1.4	5.6	6.9	2.8	8.3	5.0 (3.0; 7.9)
Chromosomal	Q900 – Q999	49.7	70.5	49.8	58.2	30.5	51.7 (44.5; 59.7)
Syndromes	Q870 – Q879	8.5	4.2	2.8	0.0	1.4	3.4 (17; 5.9)

Table 15: North East Lincolnshire PCT: Rates* of selected anomaly groups 2005 – 2009

* Per 10,000 births

North East Lincolnshire	ICD-10 Code	2005	2006	2007	2008	2009	TOTAL 95% Confidence Intervals
Central Nervous System	Q000 – Q079	25.6	15.3	34.9	5.1	30.0	22.2 (13.9; 33.6)
Eye, ear	Q100 –Q179	5.1	0.0	5.0	5.1	5.0	4.0 (1.1; 10.3)
Cardiovascular	Q200 – Q269	15.4	20.4	44.9	55.6	50.0	37.4 (26.3; 51.2)
Serious Cardiac	Q20 various	0.0	15.3	15.0	10.1	5.0	9.1 (4.2; 17.3)
Urogenital	Q500 – Q649	30.7	50.9	44.9	45.5	40.0	42.4 (30.6; 57.3)
Gastro-intestinal	Q350 – Q459	30.7	56.0	44.9	55.6	64.9	50.5 (37.5; 66.6)
Musculo-skeletal	Q180 – Q189 Q380 – Q389 Q650 – Q799	81.9	76.4	79.8	30.3	94.9	72.7 (56.9; 91.6)
Respiratory	Q300 – Q349	0.0	0.0	10.0	10.1	0.0	4.0 (1.1; 10.3)
Chromosomal	Q900 – Q999	30.7	40.8	10.0	15.2	25.0	24.2 (15.5; 36.1)
Syndromes	Q870 – Q879	5.1	5.1	0.0	0.0	5.0	3.0 (0.6; 8.9)

Table 16: North Lincolnshire PCT: Rates* of selected anomaly groups 2005 – 2009

* Per 10,000 births

North Lincolnshire	ICD-10 Code	2005	2006	2007	2008	2009	TOTAL 95% Confidence Intervals
Central Nervous System	Q000 – Q079	34.1	11.0	16.2	10.7	15.7	17.4 (9.9; 28.3)
Eye, ear	Q100 –Q179	5.7	5.5	0.0	0.0	0.0	2.2 (0.3; 7.9)
Cardiovascular	Q200 – Q269	39.8	60.5	43.3	10.7	15.7	33.7 (22.9; 47.9)
Serious Cardiac	Q20 various	22.8	16.5	21.7	5.4	15.7	16.3 (9.1; 26.9)
Urogenital	Q500 – Q649	56.9	49.5	37.9	53.7	47.1	48.9 (35.7; 65.5)
Gastro-intestinal	Q350 – Q459	39.8	38.5	21.7	21.5	36.6	31.5 (21.1; 45.3)
Musculo-skeletal	Q180 – Q189 Q380 – Q389 Q650 – Q799	79.6	49.5	75.8	80.6	68.1	70.7 (54.6; 90.1)
Respiratory	Q300 – Q349	0.0	5.5	0.0	0.0	0.0	1.1 (0.02; 6.1)
Chromosomal	Q900 – Q999	22.8	5.5	16.2	32.2	5.2	16.3 (9.1; 26.9)
Syndromes	Q870 – Q879	5.7	11.0	10.8	0.0	0.0	5.4 (1.8; 12.7)

Table 17: Northamptonshire PCT: Rates* of selected anomaly groups 2005 – 2009

* Per 10,000 births

Northampton-shire	ICD-10 Code	2005	2006	2007	2008	2009	TOTAL 95% Confidence Intervals
Central Nervous System	Q000 – Q079	20.6	18.5	16.6	21.6	20.9	19.6 (15.7; 24.2)
Eye, ear	Q100 –Q179	0.0	1.2	0.0	2.2	1.1	0.9 (0.2; 2.3)
Cardiovascular	Q200 – Q269	24.7	42.8	21.0	19.4	23.1	27.8 (23.1; 33.2)
Serious Cardiac	Q20 various	15.4	24.3	7.8	9.7	13.2	13.9 (10.6; 17.8)
Urogenital	Q500 – Q649	28.3	40.5	34.3	34.5	18.7	31.3 (26.2; 40.0)
Gastro-intestinal	Q350 – Q459	16.7	16.2	17.7	8.6	5.5	12.8 (9.7; 16.6)
Musculo-skeletal	Q180 – Q189 Q380 – Q389 Q650 – Q799	39.8	44.0	45.4	37.7	34.1	40.2 (34.4; 46.5)
Respiratory	Q300 – Q349	2.6	3.5	3.3	2.2	1.1	2.5 (1.3; 1.5)
Chromosomal	Q900 – Q999	27.0	26.6	16.6	15.1	34.1	23.7 (19.4; 28.8)
Syndromes	Q870 – Q879	2.6	4.6	5.5	1.1	2.2	3.2 (1.7; 5.4)

Table 18: Nottingham City PCT: Rates* of selected anomaly groups 2005 – 2009

* Per 10,000 births

Nottingham City	ICD-10 Code	2005	2006	2007	2008	2009	TOTAL 95% Confidence Intervals
Central Nervous System	Q000 – Q079	45.0	33.1	17.0	19.1	13.8	25.0 (18.6; 32.9)
Eye, ear	Q100 –Q179	0.0	5.1	0.0	2.4	0.0	1.5 (0.3; 4.3)
Cardiovascular	Q200 – Q269	37.1	45.8	46.0	42.9	32.2	40.7 (32.4; 50.5)
Serious Cardiac	Q20 various	23.8	20.4	21.8	31.0	16.1	22.6 (16.5; 30.1)
Urogenital	Q500 – Q649	58.3	73.8	55.7	61.9	43.7	58.4 (48.4; 69.9)
Gastro-intestinal	Q350 – Q459	31.8	12.7	9.7	21.4	27.6	20.6 (14.9; 27.9)
Musculo-skeletal	Q180 – Q189 Q380 – Q389 Q650 – Q799	55.6	89.1	63.0	78.6	43.7	65.8 (55.1; 77.9)
Respiratory	Q300 – Q349	2.6	5.1	0.0	2.4	13.8	4.9 (2.4; 9.0)
Chromosomal	Q900 – Q999	39.7	40.7	24.2	38.1	27.6	33.9 (26.4; 42.9)
Syndromes	Q870 – Q879	7.9	5.1	2.4	2.4	0.0	3.4 (1.4; 7.1)

Table 19: Nottinghamshire County PCT: Rates* of selected anomaly groups 2005 – 2009

* Per 10,000 births

Nottingham-shire County	ICD-10 Code	2005	2006	2007	2008	2009	TOTAL 95% Confidence Intervals
Central Nervous System	Q000 – Q079	30.9	19.5	21.8	15.8	14.5	20.3 (15.9; 25.4)
Eye, ear	Q100 –Q179	4.4	0.0	0.0	0.0	0.0	0.8 (0.2; 2.4)
Cardiovascular	Q200 – Q269	67.7	52.8	35.4	30.3	36.9	44.1 (37.5; 51.4)
Serious Cardiac	Q20 various	30.9	23.6	20.4	22.4	26.3	24.6 (19.8; 30.2)
Urogenital	Q500 – Q649	48.6	27.8	42.2	29.0	19.7	33.1 (27.5; 39.6)
Gastro-intestinal	Q350 – Q459	22.1	25.0	23.1	13.2	14.5	19.4 (15.2; 24.5)
Musculo-skeletal	Q180 – Q189 Q380 – Q389 Q650 – Q799	64.7	55.6	72.1	64.5	60.6	63.5 (55.6; 72.2)
Respiratory	Q300 – Q349	5.9	5.6	6.8	0.0	2.6	4.1 (2.3; 6.8)
Chromosomal	Q900 – Q999	58.8	44.5	47.6	34.2	34.2	43.5 (37.0; 50.8)
Syndromes	Q870 – Q879	7.4	1.4	1.4	1.3	0.0	2.2 (0.9; 4.3)

Table 20: Rotherham PCT: Rates* of selected anomaly groups 2005 – 2009

* Per 10,000 births

Rotherham	ICD-10 Code	2005	2006	2007	2008	2009	TOTAL 95% Confidence Intervals
Central Nervous System	Q000 – Q079	34.1	36.5	37.1	15.2	28.9	30.2 (22.2; 40.1)
Eye, ear	Q100 –Q179	3.4	0.0	3.1	0.0	6.4	2.6 (0.7; 6.6)
Cardiovascular	Q200 – Q269	37.5	26.6	40.2	21.3	38.6	32.8 (24.9; 43.1)
Serious Cardiac	Q20 various	17.0	19.9	12.4	12.2	32.2	18.6 (12.5; 26.7)
Urogenital	Q500 – Q649	27.2	13.3	37.1	12.2	19.3	21.8 (15.1; 30.5)
Gastro-intestinal	Q350 – Q459	20.4	33.2	18.6	12.2	28.9	22.5 (15.7; 31.3)
Musculo-skeletal	Q180 – Q189 Q380 – Q389 Q650 – Q799	30.7	29.9	55.7	51.8	38.6	41.7 (32.2; 53.2)
Respiratory	Q300 – Q349	6.8	6.6	3.1	0.0	9.6	5.1 (2.2; 10.1)
Chromosomal	Q900 – Q999	30.7	26.6	9.3	18.3	25.7	21.8 (15.1; 30.5)
Syndromes	Q870 – Q879	3.4	6.6	15.5	6.1	3.2	7.1 (3.5; 12.6)

Table 21: Sheffield PCT: Rates* of selected anomaly groups 2005 – 2009

* Per 10,000 births

Sheffield	ICD-10 Code	2005	2006	2007	2008	2009	TOTAL 95% Confidence Intervals
Central Nervous System	Q000 – Q079	30.9	29.8	33.1	31.4	20.9	29.2 (23.6; 35.7)
Eye, ear	Q100 –Q179	4.9	6.3	4.5	9.0	1.5	5.2 (3.0; 8.4)
Cardiovascular	Q200 – Q269	117.2	161.7	194.3	146.5	101.7	144.5 (80.2; 158.2)
Serious Cardiac	Q20 various	19.5	14.1	27.1	22.4	25.4	21.8 (17.0; 27.5)
Urogenital	Q500 – Q649	89.5	769	102.4	82.2	64.3	83.0 (73.4; 93.5)
Gastro-intestinal	Q350 – Q459	21.2	33.0	24.1	34.4	23.9	27.4 (22.0; 33.7)
Musculo-skeletal	Q180 – Q189 Q380 – Q389 Q650 – Q799	66.7	76.9	79.8	92.7	56.8	74.7 (65.6; 84.7)
Respiratory	Q300 – Q349	3.3	7.8	7.5	1.5	4.5	4.9 (2.8; 8.0)
Chromosomal	Q900 – Q999	57.0	44.0	42.2	38.9	46.4	45.5 (38.5; 53.4)
Syndromes	Q870 – Q879	1.6	9.4	9.0	4.5	6.0	6.1 (3.8; 9.5)

Fig 1: Trends in selected Neural Tube Defects 2005-9

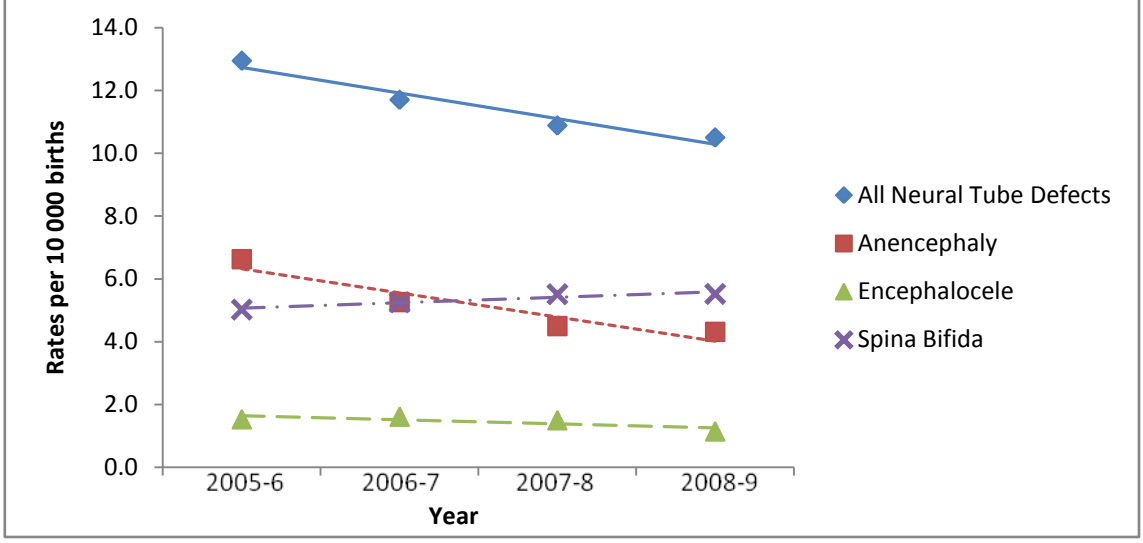
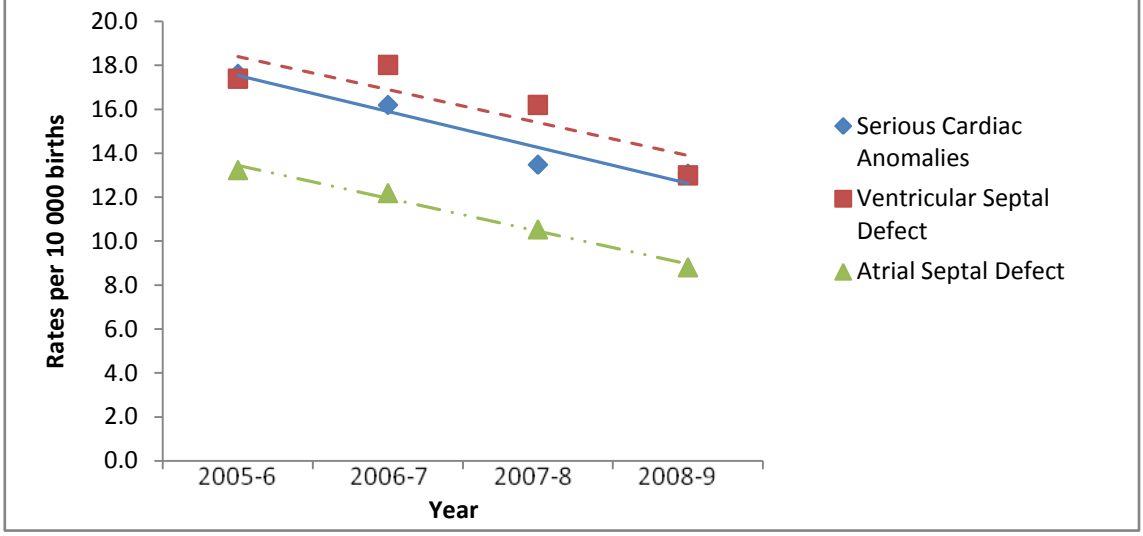


Fig 2: Trends in selected Cardiovascular Anomalies 2005-9



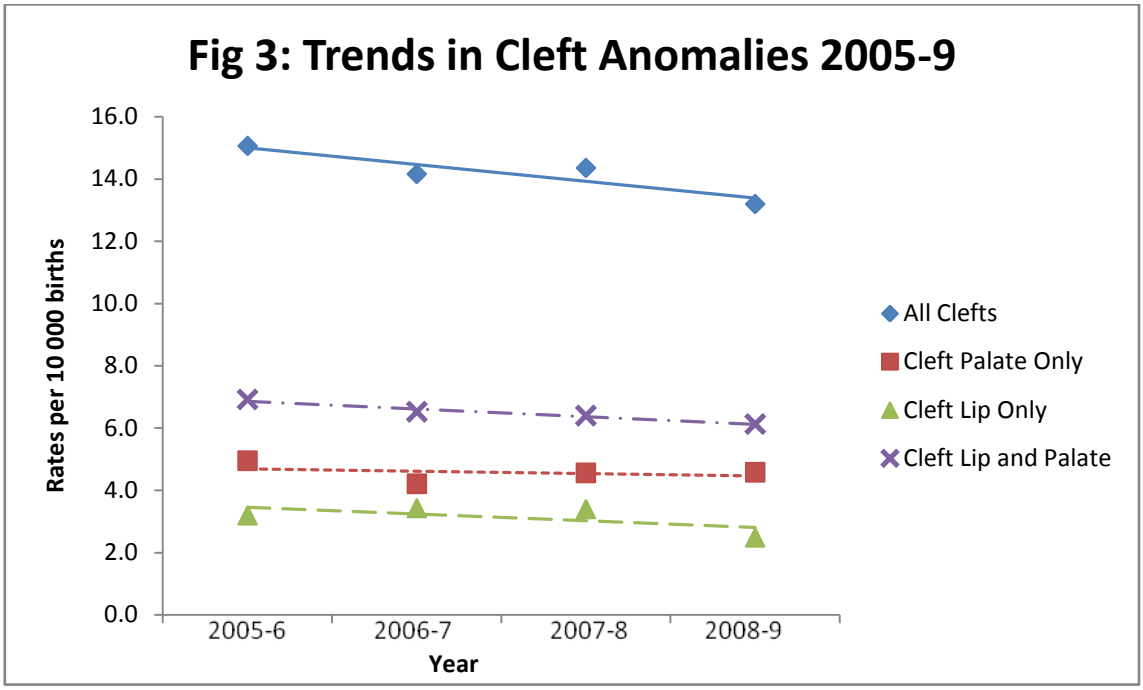


Fig 3: Trends in Cleft Anomalies 2005-9
Rates per 10 000 births
16.0
14.0
12.0
10.0
8.0
6.0
4.0
2.0
0.0
2005-6
2006-7
2007-8
2008-9
Year
All Clefts
Cleft Palate Only
Cleft Lip Only
Cleft Lip and Palate

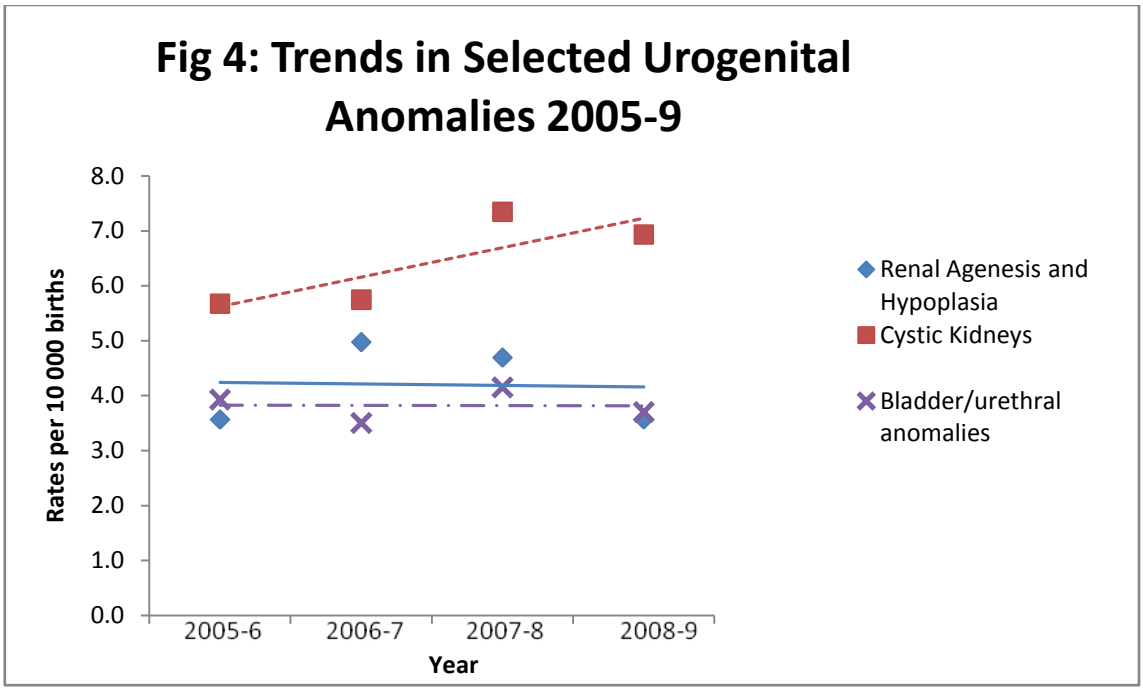


Fig 4: Trends in Selected Urogenital Anomalies 2005-9
Rates per 10 000 births
8.0
7.0
6.0
5.0
4.0
3.0
2.0
1.0
0.0
2005-6
2006-7
2007-8
2008-9
Year
Renal Agenesis and Hypoplasia
Cystic Kidneys
Bladder/urethral anomalies

Fig 5: Trends in Selected Musculoskeletal Anomalies 2005-9

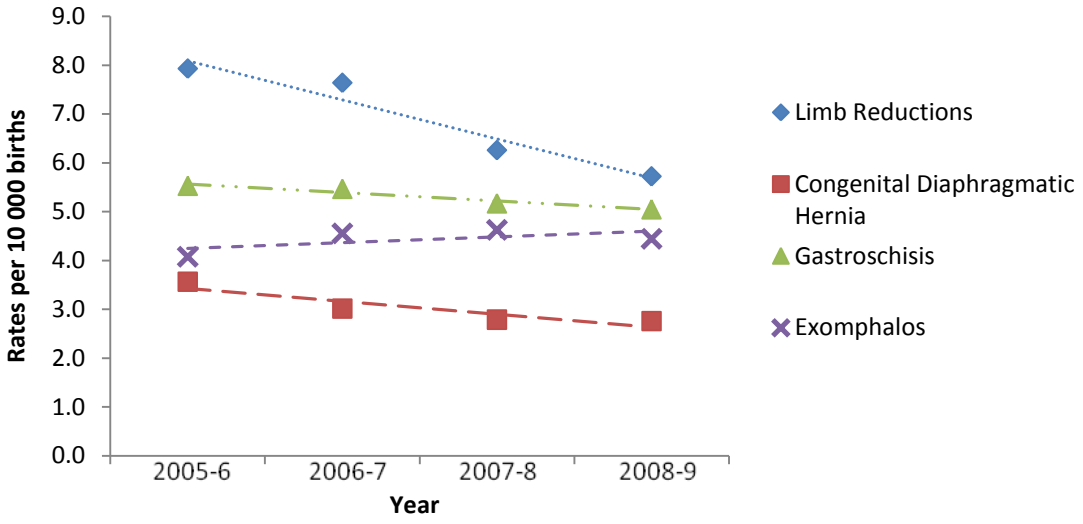


Fig 6: Trends in Selected Chromosome Anomalies 2005-9