

caris review 2014

including data 1998 – 2013

This leaflet gives key messages from congenital anomaly data collected by CARIS for 16 years, 1998 to 2013. Further information can be found on the CARIS website at www.wales.nhs.uk/caris

As always, CARIS relies heavily on clinical reporting as well as data downloads. Thank you for your contribution and support over the years.

CARIS aims to provide reliable data on congenital anomalies in Wales that can be used to:

- assess patterns of anomalies, including possible clusters and their causes.
- inform the work of screening and other health services.

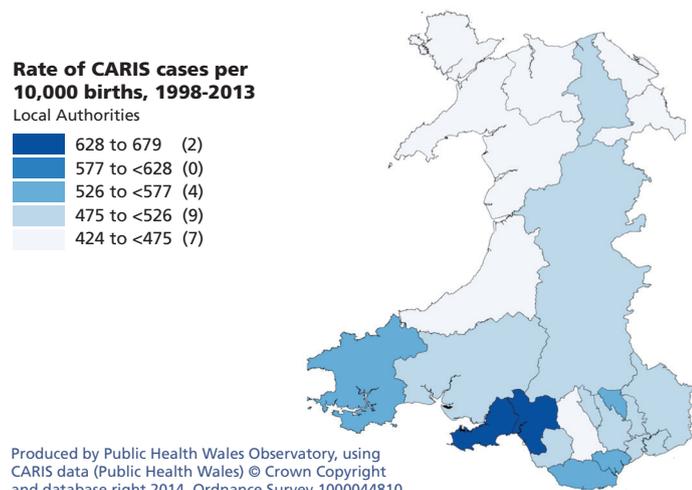
Patterns of anomalies

During 1998-2013 there were 27,816 cases of congenital anomalies reported to CARIS (23,966 live born) out of 535,785 total (live and still) births in Wales.

- The gross rate of congenital anomalies reported is 5.2%.*
- The rate of congenital anomalies in live born babies is 4.5%.
- 86.2% of cases are live born and 96.8% of these survive to the end of the first year of life. Survival is reduced with increasing complexity of anomalies.
- 60.1% of cases involve a single congenital anomaly. 11.0% of cases are associated with an underlying chromosomal disorder.
- The commonest groups of anomalies are circulatory, limb, musculoskeletal, urinary and digestive systems.

* Gross rate is the total number of cases of anomaly (regardless of whether the pregnancy ended in miscarriage, termination of pregnancy, live birth or stillbirth) as a % of the total number of live and still births.

Gross rate of CARIS cases, 1998-2013



Reporting rates

Wales compared to Britain and Europe

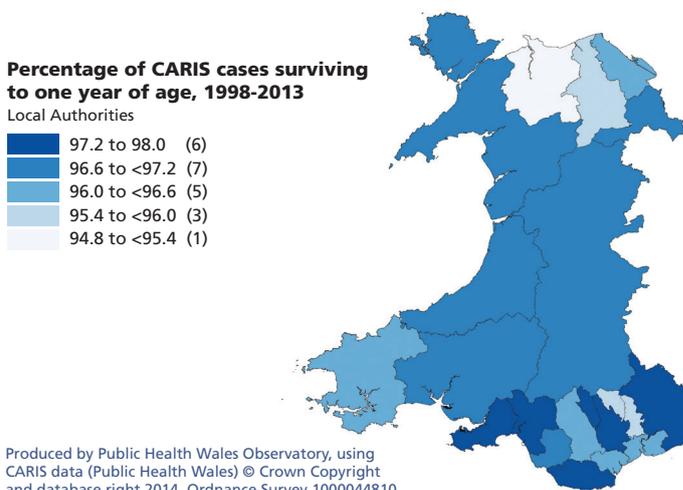
In general, prevalence rates for congenital anomalies reported by CARIS are higher than for registers in England and for many areas of Europe. We have studied this extensively and in most cases, better reporting in Wales appears to account for many of the differences. However we continue to keep the situation under review and are working to develop more robust surveillance systems for congenital anomalies in Wales.

Reporting around Wales

Reporting rates around Wales are variable with higher rates in Swansea and Neath Port Talbot. This is thought to relate to variations in reporting. Good reporting is likely to identify less severe cases and this is reflected, to some degree, in survival patterns. We will be discussing survival rates with Health Boards during 2014/15.



Percentage of CARIS cases surviving to one year of age, 1998-2013



CARIS data demonstrate the value of neonatal hearing screening

In 2003, universal neonatal hearing screening for bilateral hearing loss was introduced to Wales. Recent review of CARIS data before and after the introduction of the screening programme shows how detection in the first month of life has risen markedly since introduction of the programme, supporting early intervention for affected babies.

Congenital hearing loss, rates per 10,000 live births, Wales, 1998-2013 (CARIS data)

	Total cases	Average cases per year	Gross rate	% detected*			
				Before introduction		After introduction	
				Jan 1998 - Mar 2003	Apr 2003 - Mar 2013	In first month	After first month
All congenital hearing loss	898	56	16.8	4.7	95.3	25.8	74.2
Bilateral congenital hearing loss	598	37	11.2	4.0	96.0	29.1	70.9

Produced by Public Health Wales Observatory, using CARIS & ADBE (ONS)

*Unknown date of detection have been excluded

Neural Tube Defects still a cause for concern

Neural tube defects occur when the embryonic neural tube fails to close properly, causing serious anomalies including anencephaly and spina bifida. In 1991, the protective effect of folic acid in reducing neural tube defects was recognised.

The prevalence of neural tube defects has fallen for many years including the 1990s when recommendations on maternal preconceptional folate supplementation were published. Since then however, the decline has stalled.

In Wales, prevalence of NTDs in South Wales has remained high and levels are higher in more deprived communities. CARIS intends to look again at persistently high levels of NTDs in some parts of Wales and also to promote further discussion about alternatives to maternal use of periconceptional folic acid supplements, particularly mandatory fortification of flour.

Cases with neural tube defects, rates per 10,000 births and % of cases liveborn, Wales, 1998-2013

Anomaly	Total cases*	Average cases per year	Rate	% of cases liveborn	Trend (3-year rolling)
All neural tube defects	856	54	16.0	16.0	18.7
Anencephaly	335	21	6.3	2.4	7.9
Encephalocele	118	7	2.2	23.7	2.4
Spina bifida	415	26	7.7	24.8	8.5

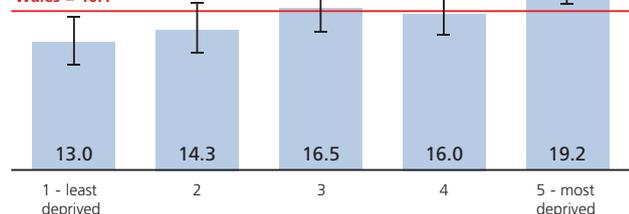
Produced by Public Health Wales Observatory, using CARIS & ADBE (ONS)

*The sum of the sub-categories is greater than the total cases of neural tube defects since a case can appear in more than one sub-category but is only counted once in the total cases of neural tube defects

Neural tube defect cases, unadjusted rate per 10,000 births by WIMD fifth, Wales, 1998-2013

Produced by Public Health Wales Observatory, using CARIS, NCCHD (NWIS) & WIMD 2011 (WG)

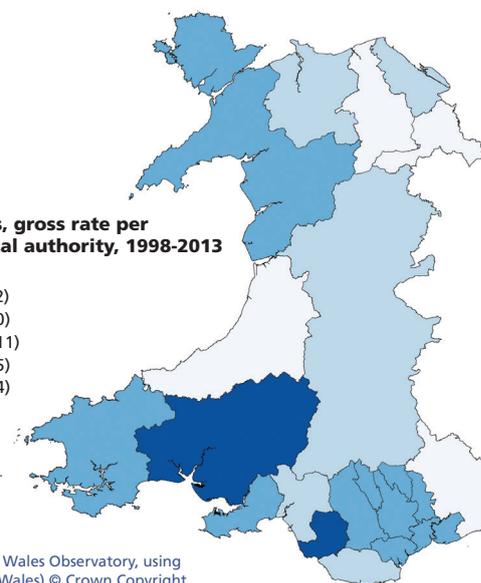
Wales = 16.1



Neural tube defects, gross rate per 10,000 births by local authority, 1998-2013

Local Authorities

21.2 to 24.2	(2)
18.3 to <21.2	(0)
15.4 to <18.3	(11)
12.5 to <15.4	(5)
9.6 to <12.5	(4)



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Data quality

CARIS is part of the EUROCAT network. Wales performs consistently well in data quality compared with other registers. For more information go to: www.eurocat-network.eu/aboutus/datacollection/dataquality/dataqualityindicators

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