

Inspiring Paediatricians to Report to CARIS

Congenital Anomaly Register & Information Service for Wales

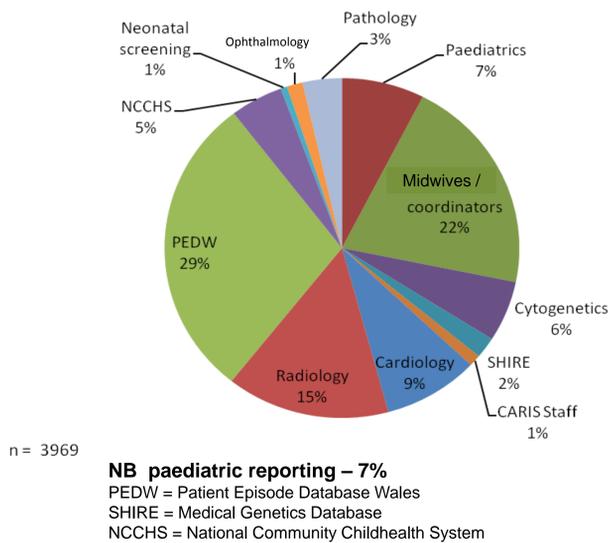
David Tucker, Margery Morgan – Public Health Wales

A surveillance study of craniosynostosis in Wales 2007-2008

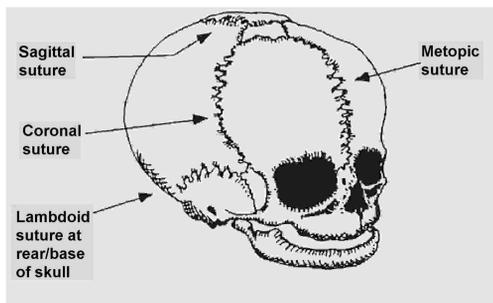
Paediatric reporting is poor.

To improve this, paediatricians were asked to report cases of craniosynostosis using the Welsh Paediatric Surveillance monthly enquiry. Questionnaires were sent to reporting paediatricians.

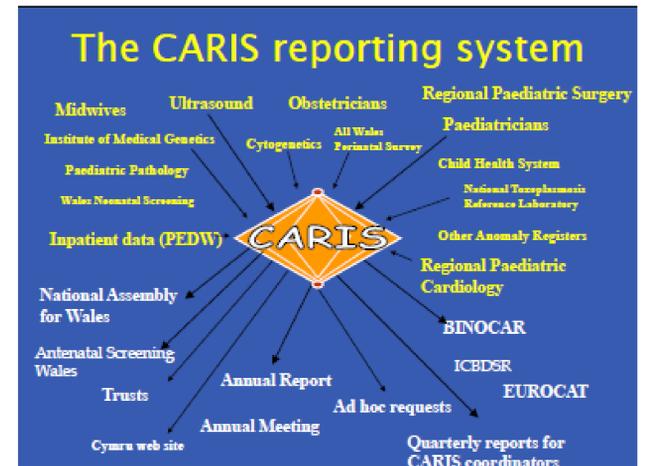
First reporting source to CARIS - 2008-2010



skull sutures



reporting mechanisms in Wales



Craniosynostosis results from premature fusion of one or more skull sutures. It is rarely diagnosed antenatally or at birth. Good reporting to the register requires notification by a paediatrician.

Table 1: Craniosynostosis: Differences between WPSU cases and Normally Reported Cases

Craniosynostosis	WPSU cases (39)	Normally Reported Cases (240)
Isolated anomaly	27 (69.2%)	157 (65.4%)
Multiple	7 (17.9%)	46 (19.2%)
Syndromic	2 (5.1%)	18 (7.5%)
Familial	1 (2.6%)	5 (2.1%)
Chromosomal	1 (2.6%)	13 (5.4%)
New Dominant	1 (2.6%)	1 (0.4%)
Antenatal detection	0 (0.0%)	9 (3.75%)
Live births	39 (100%)	226 (94.2%)
Still births	0 (0.0%)	4 (1.7%)
Terminations	0 (0.0%)	10 (4.2%)
Registered in 1 st year	22 (56.4%)	99 (41.3%)
Suture specified	39 (100%)	123 (51.3%) - significant
Genetic referral	11 (28.2%)	not recorded
Surgery planned or done	30 (76.9%)	140 (58.3%) - significant

Surveillance cases reported by paediatricians:

- ❖ 100% of sutures were specified
- ❖ Timelier registration
- ❖ Increased proportion of isolated cases
- ❖ More complete surgical data
- ❖ Prevalence rates increased (5.56 per 10,000 in 2005-06 to 7.25 per 10,000 in 2007-08)

The surveillance scheme has shown improvement in the quantity and quality of data for cases of craniosynostosis.

This effect has not continued (only 30% of sutures specified in 2009-10).

Improved paediatric reporting would increase the value of congenital anomaly data in Wales (more accurate epidemiology for healthcare planning).