

Impact of implementing IRIS on stillbirths and neonatal death data for England and Wales

Claudia Wells
Head of Mortality Analysis
Office for National Statistics

Coding Stillbirths and Neonatal deaths

- What is IRIS
- Certificate
- Current coding practice
- Analysis of IRIS coded data
- Impact

What is IRIS



© Josephine Wall http://www.josephinenwall.co.uk/

What is IRIS

- Cause of death coding software supported by Eurostat and managed by the IRIS Institute hosted by the German Institute of Medical Documentation and Information in Cologne.
- Developed to provide a common mortality coding system that can be used for coding death certificates, written in any language
- Help to improve the international comparability of mortality statistics.
- Uses components of the NCHS Mortality Medical Data System (MMDS) to code the causes of death, and to allocate the underlying cause of death.

Important changes

- An English dictionary of terms specifically for stillbirths and neonatal deaths
- Automatic coding using the same system as deaths >28days
- Requires a change in coding for stillbirths and neonatal deaths
- Assigns an underlying cause of death

Neonatal and stillbirth death certificate

- | | Duration |
|--|----------|
| a. Main diseases or conditions in infant/fetus | |
| b. Other diseases or conditions in infant/fetus | |
| c. Main maternal diseases or conditions affecting infant/ fetus | |
| d. Other maternal diseases or conditions affecting infant/ fetus | |
| e. Other relevant causes | |

Example of current coding

- | | Duration |
|---|----------|
| a. Main diseases or conditions in infant/fetus
Necrotising Enterocolitis – P77 | |
| b. Other diseases or conditions in infant/fetus
Preterm 28 weeks gestation– P073 | |
| c. Main maternal diseases or conditions affecting infant/ fetus
Maternal HIV infection – B24 | |
| d. Other maternal diseases or conditions affecting infant/ fetus
Maternal Hepatitis B Infection – O984 | |
| e. Other relevant causes | |

ONS hierarchical cause groups

Neonatal Classification

Before the onset of labour

- 1 Congenital anomalies
- 2 Antepartum infections
- 3 Immaturity related conditions

In or shortly after labour

- 4 Asphyxia, anoxia, or trauma

Postnatal

- 5 External conditions
- 6 Infections
- 7 Other specific conditions
- 9 Sudden infant deaths

Unclassified

- 0 Other conditions

Stillbirth Classification

Before the onset of labour

- 1 Congenital anomalies
- 2 Antepartum infections
- 3 Immaturity related conditions

In or shortly after labour

- 4 Asphyxia, anoxia, or trauma
- 5 External conditions
- 6 Infections
- 7 Other specific conditions

Unclassified

- 8a Asphyxia, anoxia, or trauma (antepartum)
- 8b Remaining antepartum
- 0 Other Conditions

Example of current coding

- a. Necrotising Enterocolitis – P77
- b. Preterm 28 weeks gestation– P073

- c. Maternal HIV infection – B24

- d. Maternal Hepatitis B Infection – O984

ONS cause groups

- 1 Congenital anomalies - No mention
- 2 Antepartum infections - No mention (as the infections are maternal)
- 3 Immaturity related conditions - P77 and P073

Analysis of IRIS coded data

- Developing English language dictionary
 - Events that occurred in 2010
 - 2014 Neonatal deaths, 3712 Stillbirths
1. ONS cause group based on IRIS coded mentions
 2. ONS cause group based on IRIS coded underlying cause of death

ONS cause group based on IRIS coded mentions – Neonatal Deaths

	ONS	IRIS	Difference	% Difference
1. Congenital anomalies	584	569	-15	-3
2. Antepartum infections	39	159	120	308
3. Immaturity related conditions	1132	1024	-108	-10
4. Asphyxia, anoxia or trauma	175	170	-5	-3
5. External Conditions	3	2	-1	-33
6. Infections	27	21	-6	-22
7. Other specific	14	12	-2	-14
9. Sudden Infant Death	14	12	-2	-14
0. Other	26	45	19	73

IRIS mentions Vs. ONS mentions – Neonatal Deaths

		ONS codes										
		1. Congenital anomalies	2. Antepartum infections	3. Immaturity related conditions	4. Asphyxia, anoxia or trauma	5. External Conditions	6. Infections	7. Other specific	9. Sudden Infant Death	0. Other	Total	
IRIS	1. Congenital anomalies	559	1	7					1	1	569	
	2. Antepartum infections	2	34	121				2			159	
	3. Immaturity related conditions	12	1	990	8	1	3			9	1024	
	4. Asphyxia, anoxia or trauma		1	2	164			3			170	
	5. External Conditions					2					2	
	6. Infections		1	1			19				21	
	7. Other specific	1			1		1	9			12	
	9. Sudden Infant Death								12		12	
	0. Other	10	1	11	2		2	1	2	16	45	
	Total	584	39	1132	175	3	27	14	14	26	2014	

Example 1 - Neonatal ONS codes

- | Duration |
|--|
| a. Main diseases or conditions in infant/fetus
Neonatal Sepsis – P369 |
| b. Other diseases or conditions in infant/fetus
Extreme Prematurity – P072 |
| c. Main maternal diseases or conditions affecting infant/ fetus
Chorioamnionitis – O411 |

ONS cause groups

- 1 Congenital anomalies - No mention
- 2 Antepartum infections - No mention (as infections maternal and neonatal)
- 3 Immaturity related conditions - P072

Example 1 - Neonatal IRIS codes

- | Duration |
|---|
| a. Main diseases or conditions in infant/fetus
Neonatal Sepsis – P369 |
| b. Other diseases or conditions in infant/fetus
Extreme Prematurity – P072 |
| c. Main maternal diseases or conditions affecting infant/ fetus
Chorioamnionitis – P027 |

ONS cause groups

- 1 Congenital anomalies - No mention
- 2 Antepartum infections - P027

Example 2 - Neonatal ONS codes

- a. Necrotising Enterocolitis – P77
- b. Preterm 28 weeks gestation– P073
- c. Maternal HIV infection – B24
- d. Maternal Hepatitis B Infection – O984

ONS cause groups

- 1 Congenital anomalies - No mention
- 2 Antepartum infections - No mention (as infections is maternal)
- 3 Immaturity related conditions - P77 and P073

Example 2 - Neonatal IRIS codes

- a. Necrotising Enterocolitis – P77
- b. Preterm 28 weeks gestation– P073
- c. Maternal HIV infection – P002
- d. Maternal Hepatitis B Infection – P002

ONS cause groups

- 1 Congenital anomalies - No mention
- 2 Antepartum infections - ONS cause groups include maternal condition O353 (Maternal care for (suspected) damage to fetus from viral disease in mother , now code to P002 (Fetus/newborn affected by maternal infectious and parasitic diseases) – is it correct to assume antepartum?

IRIS mentions Vs. ONS mentions – Neonatal Deaths

		ONS codes									
		1. Congenital anomalies	2. Antepartum infections	3. Immaturity related conditions	4. Asphyxia, anoxia or trauma	5. External Conditions	6. Infections	7. Other specific	9. Sudden Infant Death	0. Other	Total
IRIS	1. Congenital anomalies	559	1	7				1		1	569
	2. Antepartum infections	2	34	121				2			159
	3. Immaturity related conditions	12	1	990	8	1	3			9	1024
	4. Asphyxia, anoxia or trauma		1	2	164			3			170
	5. External Conditions					2					2
	6. Infections		1	1			19				21
	7. Other specific	1			1		1	9			12
	9. Sudden Infant Death								12		12
	0. Other	10	1	11	2		2	1	2	16	45
	Total	584	39	1132	175	3	27	14	14	26	2014

Congenital Anomalies to Immaturity

- Majority mentioned Q33.6 Hypoplasia and dysplasia of lung
- Converted to P28.0 in IRIS Hypoplasia associated with short gestation
- Majority but not all recorded mentioned prematurity of some degree

ONS cause group based on IRIS coded mentions – Stillbirths

	ONS	IRIS	Difference	% Difference
1. Congenital anomalies	540	536	-4	-1
2. Antepartum infections	30	63	33	110
4. Asphyxia, anoxia or trauma (intrapartum)	86	88	2	2
5. External conditions	6	7	1	17
7. Other specific	216	164	-52	-24
8a. Asphyxia, anoxia or trauma (antepartum)	835	876	41	5
8b. Remaining antepartum	1908	1892	-16	-1
0. Other	91	86	-5	-5

IRIS mentions Vs. ONS mentions – Stillbirths

		ONS codes								
		1. Congenital anomalies	2. Antepartum infections	4. Asphyxia, anoxia or trauma (intrapartum)	5. External conditions	7. Other specific	8a. Asphyxia, anoxia or trauma antepartum	8b. Remaining antepartum	0. Other	Total
IRIS	1. Congenital anomalies	523	1	1		1	7	3		536
	2. Antepartum infections	3	27	1		11	5	13	3	63
	4. Asphyxia, anoxia or trauma (intrapartum)			83					5	88
	5. External conditions				3			4		7
	7. Other specific				2	157	1	4		164
	8a. Asphyxia, anoxia or trauma (antepartum)		1		1	42	809	23		876
	8b. Remaining antepartum	13				5	13	1861		1892
	0. Other	1	1	1					83	86
	Total	540	30	86	6	216	835	1908	91	3712

Antepartum Infections - Stillbirths

- Other Specific Conditions:
Coding of Anhydramnios
 - IRIS codes to P02.7
 - ONS currently codes to P02.8
- Remaining antepartum:
Coding of maternal infections
 - IRIS codes to P00.2
 - Assumed antepartum?

ONS cause group based on IRIS coded underlying cause – Neonatal Deaths

	ONS	IRIS	Difference	% Difference
1. Congenital anomalies	584	509	-75	-13
2. Antepartum infections	39	109	70	179
3. Immaturity related conditions	1132	651	-481	-42
4. Asphyxia, anoxia or trauma	175	320	145	83
5. External Conditions	3		-3	-100
6. Infections	27	82	55	204
7. Other specific	14	58	44	314
9. Sudden Infant Death	14	12	-2	-14
0. Other	26	273	247	950

IRIS UCD Vs. ONS mentions – Neonatal

		ONS codes									
		1. Congenital anomalies	2. Antepartum infections	3. Immaturity related conditions	4. Asphyxia, anoxia or trauma	5. External Conditions	6. Infections	7. Other specific	9. Sudden Infant Death	0. Other	Total
IRIS	1. Congenital anomalies	502			5				1	1	509
	2. Antepartum infections	2	23		83				1		109
	3. Immaturity related conditions	16	6	618	2			2		7	651
	4. Asphyxia, anoxia or trauma	8	3	172	134	1			2		320
	5. External Conditions										
	6. Infections	4	3	55	1		18			1	82
	7. Other specific	5	1	27	12	1	2	10			58
	9. Sudden Infant Death								12		12
	0. Other	47	3	172	26	1	4	1	2	17	273
	Total	584	39	1132	175	3	27	14	14	26	2014

ONS cause group based on IRIS coded underlying cause –Stillbirths

	ONS	IRIS	Difference	% Difference
1. Congenital anomalies	540	445	-95	-18
2. Antepartum infections	30	47	17	57
3. Immaturity related conditions	86	72	-14	-16
4. Asphyxia, anoxia or trauma	6	2	-4	-67
5. External Conditions	216	159	-57	-26
6. Infections	835	796	-39	-5
7. Other specific	1908	2083	175	9
9. Sudden Infant Death	91	108	17	19
0. Other	540	445	-95	-18

IRIS UCD Vs. ONS mentions – Stillbirth

	ONS codes									
	1. Congenital anomalies	2. Antepartum infections	4. Asphyxia, anoxia or trauma (intrapartum)	5. External conditions	7. Other specific	8a. Asphyxia, anoxia or trauma (antepartum)	8b. Remaining antepartum	0. Other	Total	
IRIS	1. Congenital anomalies	441			1	1	2		445	
	2. Antepartum infections	6	22	1	6		10	2	47	
	4. Asphyxia, anoxia or trauma (intrapartum)	2		67				3	72	
	5. External conditions	1						1	2	
	7. Other specific	9	1	2	2	139	4	2	159	
	8a. Asphyxia, anoxia or trauma (antepartum)	6	1		1	30	740	18	796	
	8b. Remaining antepartum	73	2		3	40	90	1875	2083	
	0. Other	2	4	16					108	
	Total	540	30	86	6	216	835	1908	91	3712

Further work

- Implications for UK data
- Publication of dual coding data for 2012
- Publication of mapping document
- Publication of the stillbirth and neonatal cause of death dictionaries

Thank you

- Any questions?
- What do you need in terms of impact analysis
- What are your European experiences?
 - Do you use the WHO recommended certificate – how do you code the maternal conditions, underlying cause
 - Any other experiences of IRIS