

# BURY, ROCHDALE & OLDHAM Child Death Overview Panel



## Annual Report

April 2013 – March 2014

# Contents

1.	Introduction.....	4
	- A Summary of the Key Findings.....	4
	- Activity of the Child Death Overview Panel.....	5
2.	Roles and Responsibilities of the Child Death Overview Panel (CDOP).....	6
3.	Panel Membership.....	7
4.	Panel Attendance.....	8
5.	2013/2014 Notifications to the CDOP.....	9
6.	Data by Childs Year of Death.....	10
7.	Cases Closed Between 1 April 2013 and 31 March 2014.....	11
	- Time taken for Completion and Closure of Cases.....	11
	- Categorisation of Cases.....	12
	- Categorisation of Preventability.....	13
8.	Child Population across the Local Authorities.....	15
9.	Childs Age at Death.....	17
10.	Child Deaths Under 1.....	22
	- Neonatal Deaths.....	22
	- Smoking during Pregnancy.....	22
	- Prematurity & Birth Weight.....	23
	- Multiple Pregnancies.....	25
11.	Gender across the Local Authorities.....	26
	- Life expectancy.....	26
12.	Gender of Child Deaths.....	27
13.	Ethnicity across the Local Authorities.....	29
14.	Ethnicity of Child Deaths.....	30

# Contents continued

15.	Consanguinity.....	32
-	Genetics & Consanguinity.....	32
-	Consanguinity & Child Deaths.....	33
-	Consanguinity and the Associated Health Risks.....	33
-	How does Consanguinity affect the Population?.....	34
-	Consanguinity and Children with Disabilities.....	36
16.	Levels of Deprivation.....	37
-	Quintiles.....	38
17.	Sudden Unexpected Death in Infancy (SUDI) .....	41
-	SUDI Year on Year.....	41
-	Safe Sleeping Information.....	43
18.	Suicides.....	44
19.	Ingestion of Hazardous Substances.....	45
20.	Recommendations.....	47
21.	2013/2014 Action Plan.....	50

# 1. Introduction

The Bury, Rochdale and Oldham Child Death Overview Panel (CDOP) would like to welcome you to the sixth annual report, which reviews cases referred to the panel between 1 April 2013 and 31 March 2014.

In April 2008 Bury, Rochdale and Oldham joined to form a tripartite arrangement following the recommendation made by the Department for Education (DfE) that CDOPs require a total population of 500,000 or higher. The joint working of the three local authorities provides a wider data set to conduct analysis and investigate emerging trends.

The Bury, Rochdale and Oldham Child Death Overview Panel (CDOP) is 1 of 4 CDOPs in Greater Manchester.

Manchester North	Bury, Rochdale and Oldham
Manchester South	Tameside, Trafford and Stockport
Manchester West	Bolton, Salford and Wigan
Manchester City	Manchester

As a subgroup of the Local Safeguarding Children Board (LSCB), the CDOP reports information and themes back to each of the LSCBs via the annual report and on an ad hoc basis.

The Greater Manchester Child Death Database was implemented across the four CDOPs and is populated by the CDOP Officers with information for each child death notification received. The database contains information regarding all deaths referred to the panel and is an extremely useful tool when extracting data to support the annual report and information requests from the DfE.

The CDOP continues to distribute information for parents via the Register Office. Registrars across Greater Manchester agreed to distribute the Foundation for the Study of Infant Deaths (FSID) booklet 'The child death review: A guide for parents and carers' to parents when registering a child death to ensure information is provided at an appropriate time. If parents have any queries they can put these in writing to the CDOP to request further information regarding the process. The Lullaby Trust (formally known as FSID) has recently revised the leaflet '[The Child Death Review: A Guide for Parents and Carers](#)' which will be continued to be distributed by the Registrar.

## A Summary of the Key Findings

The report analyses the total number of child deaths reported to the CDOP between 1 April 2013 to 31 March 2014 and breaks these figures down into each borough to identify any themes locally.

- Since the CDOP was established in 1 April 2008 to 31 March 2013 there have been a total of 409 child death notifications reported to panel.
- Between 1 April 2013 and 31 March 2014 the CDOP received a total of 74 child death notifications
- With 33 of the 74 child deaths Oldham received the largest number of notifications totalling 44%. Of the 3 boroughs joint child population (149,281) Oldham has the largest child population (56,557) totalling 38%.
- Of the 59 cases closed 18 (32%) were categorise as having modifiable factors and 41 (69%) categorised as having no modifiable factors. Of the 18 modifiable cases the largest number of deaths were categorised as perinatal/neonatal (8, 44%). Of the 8 perinatal/neonatal deaths 7 Mothers smoked during pregnancy which the CDOP deem as modifiable. 5 (28%) of modifiable cases were categorised as trauma and other external factors, 3 of which were involved in a road traffic collision where the child was either the driver of the vehicle or a passenger.
- All three of the local authorities found the highest number of deaths occurred in neonates (deaths within 28 days of life) with a joint total of 43% of the overall deaths. Another large proportion of the deaths occurred in children aged 29 - 365 days, calculating 23%. If we combine the two categories this would indicate that 49 of the 74 child deaths (66%) occurred within the first year of life.
- Of the 74 child death notifications 48 (65%) of these were male and 26 (35%) were female. In comparison to the joint CDOP child population there is a higher percentage of males (51%) than females (49%)

- There was a 50/50 split in the number of child deaths of White/White British ethnicity 37 (50%) and children from the Black Minority Ethnic community 37 (50%).
- Of the 37 BME child deaths across Bury, Rochdale and Oldham, 23 of these were of Pakistani heritage totalling 62% of the BME deaths. Children of Bangladeshi heritage accounted for 16% (6) of the total BME deaths, making these two ethnic groups the most prevalent within the BME community.
- Of the 37 BME deaths, consanguinity was relevant and directly linked to 27% (10) of the child deaths.
- In comparison to Bury and Rochdale, Oldham has a much larger percentage of child deaths from the BME community. Of the 33 Oldham child deaths 22 (66%) of these were from the BME community. Oldham has a much higher percentage of child deaths from the Pakistani community in comparison to Bury and Rochdale.
- Of the 15 cases where it was recorded that Mother and Father were related 10 of these deaths were directly linked to parents being first cousins making up 14% of the total 74 deaths.
- All 10 of the children were of Pakistani heritage. In 5 of the 10 families, siblings have also been diagnosed with the same inherited life limiting condition and/or there has been a previous death of a sibling.
- The highest number of deaths linked to consanguinity occurred in Oldham (4, 40%) and Rochdale (4, 40%)
- Statistics from the Children with Disabilities Team highlighted a disproportion number of children from the BME community known to the service in comparison to the BME child population. A common theme across the three local authorities is that children with disabilities of Pakistani heritage are the most prevalent ethnic group within the BME community. The figures suggest that there is a link between consanguinity and children with disabilities given that consanguineous relationship and cousin marriage is mostly practiced within the Pakistani community.
- Of the 74 child deaths the largest number of deaths occurred where the child/family resided in areas of deprivation (quintile 1 and 2) totalling 39% (51) of the total deaths. Of these 51 child deaths in quintile 1 and 2 a large percentage of the deaths occurred in neonates (18, 35%)
- The CDOP was notified of 7 potential SUDI child deaths. Following the conclusion of a post mortem examination and/or inquest the Pathologist and the Coroner has ascertained the cause of death as Unascertained/Natural Causes (of unascertained origin) for 5 of the SUDI deaths. Of the 5 confirmed SUDI deaths co-sleeping on a sofa or in a parental bed was identified in 3 of the cases where overheating was documented as a risk factor.

## Activity of the Child Death Overview Panel (CDOP)

Over the years the CDOP has become more robust in data collection to identify specific patterns and trends in child deaths. The more detailed the information the more in-depth analysis can be performed to support local and regional emerging themes. Working collaboratively with CDOPs across Greater Manchester is extremely beneficial to benchmark the CDOP with neighbouring local authorities. Not only does this provide a much larger footprint for data analysis and comparative data but also provides the opportunity for CDOPs to effectively work together on raising awareness of specific issues.

In recent years the 4 CDOPs have extracted data and merged the information to form the basis of the Greater Manchester Child Death Overview Annual Report. The report provides an overview of cases closed between 1 April to 31 March and can be found via the [Greater Manchester Safeguarding Children Partnership](#) website.

In February 2014 the 3 Local Safeguarding Children Boards (LSCB) appointed Andrea Fallon, Consultant in Oldham Public Health as the new CDOP Chair. It was agreed that Public Health are to chair the CDOP for the foreseeable future and will rotate the position across the 3 boroughs every 2 years. Andrea Fallon has agreed to Chair the CDOP until 2015 when role will be rotated to either Bury or Rochdale Public Health.

Unfortunately the post of the CDOP Officer was vacant for 4 months from April 2014 to July 2014. This resulted in the delay of producing the annual report but has allowed the panel to gather further information in relation to the cases discussed in the report.

## 2. Roles and Responsibilities of the Child Death Overview

The Child Death Overview Panel (CDOP) operates in line with the [Chapter 5: Child Death Reviews of Working Together 2013](#)

The Local Safeguarding Children Board (LSCB) functions in relation to child deaths are set out in Regulation 6 of the LSCBs Regulations 2006, made under section 14(2) of the Children Act 2004. The LSCB is responsible for:

- a) Collecting and analysing information about each death with a view to identifying—
  - i) Any case giving rise to the need for a review mentioned in regulation 5(1)(e);
  - ii) Any matters of concern affecting the safety and welfare of children in the area of the authority;
  - iii) Any wider public health or safety concerns arising from a particular death or from a pattern of deaths in that area; and
- b) Putting in place procedures for ensuring that there is a coordinated response by the authority, their Board partners and other relevant persons to an unexpected death.

The functions of the CDOP include:

- reviewing all child deaths up to the age of 18, excluding those babies who are stillborn and planned terminations of pregnancy carried out within the law;
- collecting and collating information on each child and seeking relevant information from professionals and, where appropriate, family members;
- discussing each child's case, and providing relevant information or any specific actions related to individual families to those professionals who are involved directly with the family so that they, in turn, can convey this information in a sensitive manner to the family;
- determining whether the death was deemed preventable, that is, those deaths in which modifiable factors may have contributed to the death and decide what, if any, actions could be taken to prevent future such deaths;
- making recommendations to the LSCB or other relevant bodies promptly so that action can be taken to prevent future such deaths where possible;
- identifying patterns or trends in local data and reporting these to the LSCB;
- where a suspicion arises that neglect or abuse may have been a factor in the child's death, referring a case back to the LSCB Chair for consideration of whether an SCR is required;
- agreeing local procedures for responding to unexpected deaths of children; and
- cooperating with regional and national initiatives – for example, with the National Clinical Outcome Review Programme – to identify lessons on the prevention of child deaths.

The aggregated findings from all child deaths should inform local strategic planning, including the local Joint Strategic Needs Assessment, on how to best safeguard and promote the welfare of children in the area. Each CDOP should prepare an annual report of relevant information for the LSCB. This information should in turn inform the LSCB annual report.

### 3. Panel Membership


The Child Death Overview Panel (CDOP) membership is made up of multi-agency professionals from across the three local authorities. Membership is rotated across the boroughs every 3 years.

<b>Name</b>	<b>Position</b>	<b>Organisation</b>	<b>Representing the Local Authority</b>
Andrea Fallon	CDOP Chair Consultant in Public Health	Public Health	Oldham
Abdul Rehman	SUDI Paediatrician	Pennine Acute Hospitals	Bury, Rochdale & Oldham
Alison Kelly	Named Nurse for Safeguarding Children & Adults	HMR Community Services	Rochdale
Amanda Smith	Child Safeguarding Lead	Pennine Care (Mental Health)	Bury, Rochdale & Oldham
Chris Howard	Paediatrician	Pennine Care	Oldham
David Devane	Safeguarding Lead for Education	Education	Oldham
Hazel Chamberlain	Designated Nurse - Children's Safeguarding	NHS Rochdale Clinical Commissioning Group	Rochdale
Laurene Mannix	Named Nurse - Safeguarding Children	Pennine Acute Trust	Bury, Rochdale & Oldham
Maxine Lomax	Designated Nurse for Safeguarding (Children and Adults)	NHS Bury Clinical Commissioning Group (CCG)	Bury
Rob Rifkin	Designated Doctor for Safeguarding Children	Bury CCG and HMR CCG	Bury & Rochdale
Sandra Bruce	Children's Service Manager (Safeguarding Unit)	Social Care	Rochdale
Kirsty Leyden / Tim Cooke	Detective Sergeants	Greater Manchester Police	Bury, Rochdale & Oldham


## 4. Panel Attendance

The below table provides a summary of the 2013/14 attendance of panel members.

Name	Organisation	June 2013	September 2013	December 2013	February 2014
Andrea Fallon	Chair (Oldham Public Health)			X	X
Mick Lay	Independent Chair	X	X		
Abdul Rehman	SUDC Paediatrican	X	X		
Alison Kelly	Pennine Community Service				
Amanda Smith	Pennine Care (Mental Health)			X	
Chris Howard	Oldham, Pennine Care		X		X
David Devane	Oldham, Education	X	X	X	X
Donna Green	Bury LSCB Development Manager	X	X	X	
Elizabeth Wilson	Rochdale, Public Health	X	X	X	
Hazel Chamberlain	Rochdale, Clinical Commissioning Group	X		X	X
Kim Gaskell	Pennine Acute Hospitals	X	X	X	
Kirsty Leyden/ Nicola Fagan/ Tim Cooke	Greater Manchester Police	X	X	X	X
Laurene Mannix	Pennine Acute Hospitals				X
Sandra Bruce	Rochdale, Social Care	X (AM Only)		X	X
Stephanie Davern	CDOP Officer	X	X	X	X
<b>Guests/Attendees on behalf of an absent panel member</b>					
Andy Searle	(Interim) Independent Chair			X	
Deborah Butcher	On behalf of Alison Kelly				X
Deepak Upadhyay	On behalf of Chris Howard	X			
Glynis Williams	Observer: Oldham Social Care	X (AM Only)			
Mike Leaf	Observer: Lancashire CDOP Chair	X			

 In attendance

 No longer a CDOP member

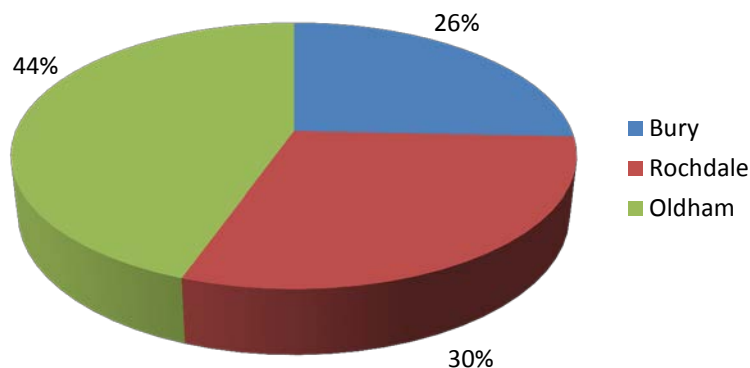
 Apologies or did not attend

At the December 2013 CDOP the group agreed to change the format of the panel meetings from 4 full day meetings to 6 bi-monthly meetings annually effective from 2014 onwards.



## 5. 2013/2014 Notifications to CDOP

From the 1 April 2013 to 31 March 2014 the CDOP received a total of 74 child death notifications aged 0 – 17 years of age.



Bury	19	26%
Rochdale	22	30%
Oldham	33	44%
Total	74	

Since the CDOP was established on 1 April 2008 to the 31 March 2014 there have been a total of 409 child death notifications reported to panel. The below table provides a breakdown of year on year data based on the year the death was notified to the CDOP.

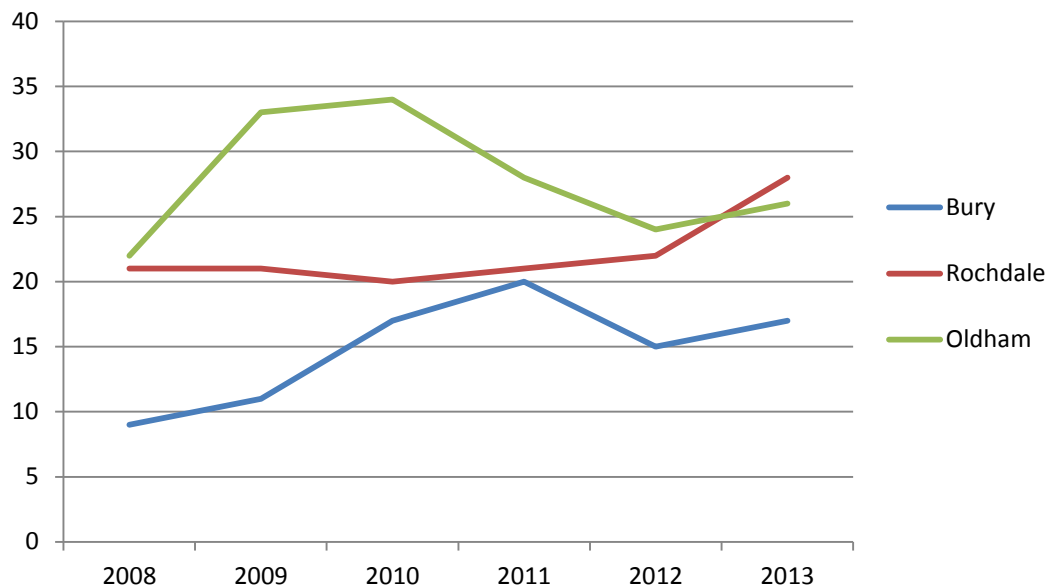
	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	Total
Bury	5	15	18	21	16	19	94
Rochdale	17	24	19	26	27	22	135
Oldham	23	27	37	36	22	33	178
Total	45	66	75	84	65	74	409
*Out of Area	0	<3	<3	0	<3	0	3

\*NB: In 2009/10 there was an error in information and the panel discussed a Lancashire child death where the address was mistaken as Bury. This case was included in the 2009/10 annual report statistics for Bury but referred onto the Lancashire CDOP for information. In 2010/11 the CDOP reviewed a Tameside death where the child died following an unexpected accident in the area of Rochdale. In 2013/14 the panel reviewed a Tameside baby as professionals involved were linked to the family.

These 3 cases have not been included in the statistics, nor will they be used throughout the report to ensure that the data is that of only Bury, Rochdale and Oldham.

## 6. Data by Childs Year of Death

Each year the CDOP bases the Annual Report data set on the number of child deaths referred to the CDOP from 01 April to 31 March. The data below shows the number of child deaths categorised by the year the death occurred. These figures may change slightly if in future the panel receives a late notification from previous years. The data for 2014 will be included in the 2014/2015 CDOP Annual Report.



	Bury	Rochdale	Oldham	Total
2008	9	21	22	52
2009	11	21	33	65
2010	17	20	34	71
2011	20	21	28	69
2012	15	22	24	61
2013	17	28	26	71
	89	133	167	389

Although there has been no significant rise or fall in the number of deaths since 2008 the above statistics indicate the largest number of child deaths occurred in 2010 and 2013. Whilst the fewest number of child deaths occurred in 2008 it is a possibility that there was potentially a lack in notifications to the CDOP as the panel was newly established. There was initially a discussion amongst CDOPs regarding notifications of infant deaths under 24 weeks gestation, until the Department of Education revised Working Together to Safeguard Children in 2010 to state that CDOPs are to discuss 'all child deaths up to the age of 18 years (excluding both those babies who are stillborn and planned terminations of pregnancy carried out within the law)'

Excluding 2013, Oldham has been the local authority with the largest number of child deaths year on year and has the largest child population of the three local authorities. Of the three boroughs Bury continues to have the lowest number of child deaths year on year and has smallest child population of the three local authorities.

From January 2014 to March 2014 there have been 20 child death notifications. Data for the total number of deaths in 2014 continues to be collated and will be provided in the 2014/15 Annual Report.

## 7. Cases Closed Between 1 April 2013 & 31 March 2014

From 1 April 2013 to 31 March 2014 the CDOP discussed and closed a total of 59 cases.

Bury	13	22%
Rochdale	20	34%
Oldham	24	41%
Out of Area	<3	3%
Total	59	

Of the 59 cases closed 23 (39%) were notified to the CDOP in 2013/14 and the remaining 36 (61%) cases were referred prior to 1 April 2013. A number of these cases were subject to investigations (such as Post Mortem Examination, Inquests, Police/CPS Prosecution, Serious Case Reviews, Internal Review/Audit) thus prolonging the discussion and closure of the cases.

Year Referred to CDOP	
2010/11	6
2011/12	5
2012/13	25
2013/14	23

As the Annual Report bases its data set on the number of notifications received, in-depth analysis for the 36 cases referred prior to 1 April 2013 is detailed in previous annual reports.

Of the 74 cases referred to the CDOP between 1 April 2013 to 31 March 2014, 23 (31%) of these were closed within the same year and 51 (69%) remain open for discussion.

Under the revised Rule 8 of the Coroners (Inquest) Rules 2013, Coroners are now required to complete an inquest within 6 months of the date on which the Coroner is made aware of the death, or as soon as is reasonably practicable. The change in legislation will significantly reduce the length of time between the date of notification and date closed for cases subject to post mortem examination and/or inquisition.

### Time taken for Completion and Closure of Cases

Of the 59 cases closed between 1 April 2013 and 31 March 2014 a large proportion of the cases were closed within 6 months of the date of notification. Whilst 32% (19) of the cases remained open for over a year 16 (84%) of these were subject to some form of investigation such as post mortem, inquest, police investigation/CPS prosecution, serious case review, internal review etc.

Time taken to Close Cases		
Under 6 months	26	44%
6 to 7 months	5	8%
8 to 9 months	4	7%
10 to 11 months	4	7%
12 months	<3	2%
Over 1 year	19	32%
Total	59	

## Categorisation of Cases

Once the CDOP has discussed a case and are in agreement that sufficient information has been collated, a Form C Analysis Profroma is completed by multi-agency professionals. The Department for Education national templates assist the panel to review the circumstances leading to death and identify any emerging trends.

The Department for Education requires CDOPs to allocate each child death under one of the following categories:

- 1. Deliberately inflicted injury, abuse or neglect**  
This includes suffocation, shaking injury, knifing, shooting, poisoning & other means of probable or definite homicide; also deaths from war, terrorism or other mass violence; includes severe neglect leading to death.
- 2. Suicide or deliberate self-inflicted harm**  
This includes hanging, shooting, self-poisoning with paracetamol, death by self-asphyxia, from solvent inhalation, alcohol or drug abuse, or other form of self-harm. It will usually apply to adolescents rather than younger children.
- 3. Trauma and other external factors**  
This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in pre-school children, anaphylaxis & other extrinsic factors. Excludes deliberately inflicted injury, abuse or neglect. (category 1).
- 4. Malignancy**  
Solid tumours, leukaemias & lymphomas, and malignant proliferative conditions such as histiocytosis, even if the final event leading to death was infection, haemorrhage etc.
- 5. Acute medical or surgical condition**  
For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy.
- 6. Chronic medical condition**  
For example, Crohn's disease, liver disease, immune deficiencies, even if the final event leading to death was infection, haemorrhage etc. Includes cerebral palsy with clear post-perinatal cause.
- 7. Chromosomal, genetic and congenital anomalies**  
Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease, cystic fibrosis, and other congenital anomalies including cardiac.
- 8. Perinatal/neonatal event**  
Death ultimately related to perinatal events, eg sequelae of prematurity, antepartum and intrapartum anoxia, bronchopulmonary dysplasia, post-haemorrhagic hydrocephalus, irrespective of age at death. It includes cerebral palsy without evidence of cause, and includes congenital or early-onset bacterial infection (onset in the first postnatal week).
- 9. Infection**  
Any primary infection (ie, not a complication of one of the above categories), arising after the first postnatal week, or after discharge of a preterm baby. This would include septicaemia, pneumonia, meningitis, HIV infection etc.
- 10. Sudden unexpected, unexplained death**  
Where the pathological diagnosis is either 'SIDS' or 'unascertained', at any age. Excludes Sudden Unexpected Death in Epilepsy (category 5).

This classification is hierarchical: where more than one category could reasonably be applied, the highest up the list is marked.

Categorisation of Death	Bury	Rochdale	Oldham	Out of Area	Total	
Perinatal/neonatal event	7	7	9	<3	24	41%
Chromosomal, genetic and congenital anomalies	<3	4	3	0	9	15%
Acute medical or surgical condition	0	3	5	0	8	14%
Trauma and other external factors	0	3	4	<3	8	14%
Malignancy	<3	0	<3	0	4	7%
Chronic medical condition	0	<3	<3	0	3	5%
Infection	<3	<3	0	0	<3	3%
Suicide or deliberate self-inflicted harm	<3	0	0	0	<3	1%
Deliberately inflicted injury, abuse or neglect	0	0	0	0	0	0%
Sudden unexpected, unexplained death	0	0	0	0	0	0%
Total	13	20	24	<3	59	100%

The largest number of deaths occurred in the category perinatal/neonatal event with 24 (41. %) of the 59 cases. Of the 24 perinatal/neonatal deaths 2 (8%) were full term pregnancies and 22 (92%) were born premature (<37 weeks gestation)

- 21 Extremely premature (<26 weeks gestation)
- 2 Premature (26 - <36 weeks gestation)

Of the 24 perinatal/neonatal deaths 21 (87%) babies were delivered at a low birth weight of less than 2500 grams.

Another large percentage of the deaths were represented in chromosomal, genetic and congenital anomalies totalling 9 deaths (15 %), 5 (55%) of which consanguinity was recorded as a contributing factor.

## Categorisation of Preventability

For each case discussed and closed the CDOP professionals will determine the categorisation of preventability. In line with the Department for Education, the CDOP must categorise the case under one of the following:

### 1. Modifiable factors identified

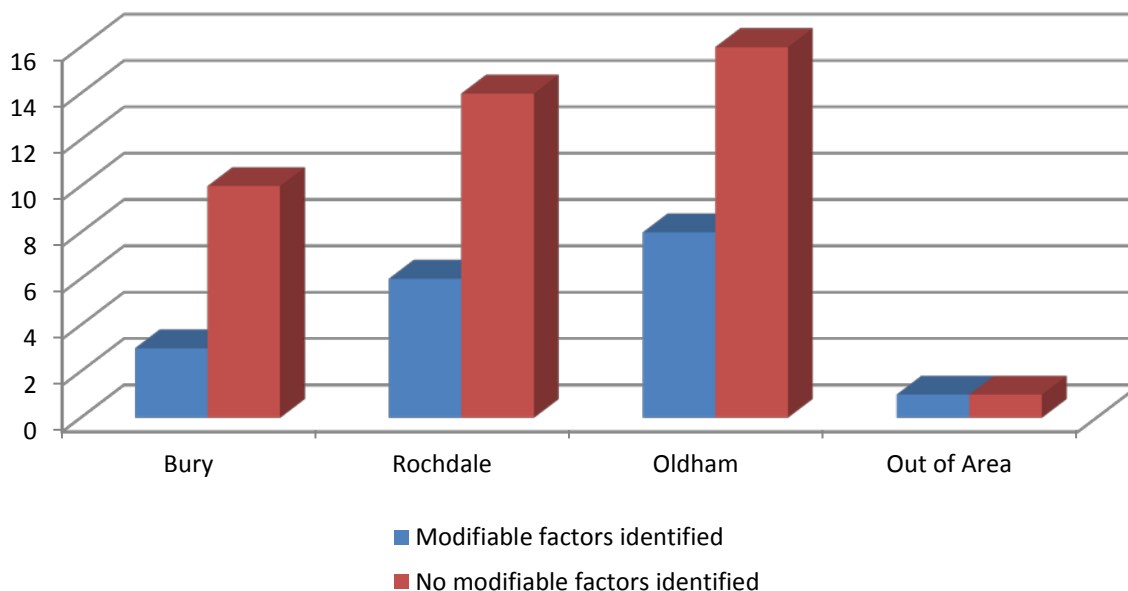
The panel have identified one or more factors, in any domain, which may have contributed to the death of the child and which, by means of locally or nationally achievable interventions, could be modified to reduce the risk of future child deaths

### 2. No Modifiable factors identified

The panel have not identified any potentially modifiable factors in relation to this death

### 3. Inadequate information upon which to make a judgement

NB this category should be used very rarely indeed.



	Modifiable factors identified	No modifiable factors identified
Bury	3	10
Rochdale	6	14
Oldham	8	16
Out of Area	<3	<3
Total	18 (31%)	41 (69%)

Of the 59 cases closed between 1 April 2013 and 31 March 2014 the panel identified modifiable factors in 18 (31%) deaths. The remaining 41 (69%) cases were categorised as having no modifiable factors.

Of the 18 modifiable cases the largest number of deaths were categorised as perinatal/neonatal (8, 44%). Of the 8 perinatal/neonatal deaths 7 Mothers smoked during pregnancy which the CDOP deem as modifiable. Due to the associated health risks linked to smoking in pregnancy all 4 CDOPs across Greater Manchester have agreed to categorise neonatal/premature deaths as having modifiable factors where Mother smoked in pregnancy.

5 (28%) of modifiable cases were categorised as trauma and other external factors, 3 of which were involved in a road traffic collision where the child was either the driver of the vehicle or a passenger.

Modifiable Factors and the category of death	Modifiable factors identified	
Perinatal/neonatal event	8	44%
Trauma and other external factors	5	28%
Chromosomal, genetic and congenital anomalies	3	17%
Acute medical or surgical condition	<3	11%
Total	18	100%

## 8. Child Population across the Local Authorities

The below table provides information from the Office of National Statistics (ONS) 2011 Census, providing a breakdown of age across the child population for children aged 0 – 17 years.

Age		England	North West	Greater Manchester	Bury	Rochdale	Oldham	CDOP Total
Infants, Children & Young People	Age 0 to 4	3,318,449	432,091	181,245	12,235	14,754	16,491	43,480
	Age 5 to 9	2,972,632	392,166	158,523	11,108	13,148	15,422	39,678
	Age 10 to 14	3,080,929	412,407	160,304	11,361	13,925	15,337	40,623
	Age 15 to 17	1,964,950	265,375	101,552	7,248	8,945	9,307	25,500
<b>Total</b>		<b>11,336,960</b>	<b>1,502,039</b>	<b>601,624</b>	<b>41,952</b>	<b>50,772</b>	<b>56,557</b>	<b>149,281</b>
Adults	Age 18 to 19	1,375,315	191,462	74,759	4,297	5,480	5,749	-
	Age 20 to 24	3,595,321	489,640	203,899	10,688	14,005	14,586	-
	Age 25 to 29	3,650,881	466,582	200,933	11,622	14,111	15,177	-
	Age 30 to 44	10,944,271	1,394,536	560,081	37,977	42,914	44,945	-
	Age 45 to 59	10,276,902	1,397,119	500,860	37,272	41,147	42,055	-
	Age 60 to 64	3,172,277	439,644	150,623	11,712	12,454	12,875	-
	Age 65 to 74	4,552,283	627,742	211,280	16,292	16,642	18,280	-
	Age 75 to 84	2,928,118	394,596	129,230	9,623	10,367	10,465	-
	Age 85 to 89	776,311	99,316	32,995	2,397	2,632	2,760	-
Age 90 & over	403,817	49,501	16,244	1,228	1,175	1,448	-	
<b>Total Population</b>		<b>53,012,456</b>	<b>7,052,177</b>	<b>2,682,528</b>	<b>185,060</b>	<b>211,699</b>	<b>224,897</b>	<b>621,656</b>

The ONS data shows the total child population across the three local authorities as 149,281, with the highest number of children being ages 0 to 4 at 29.1%.

Age 0 to 4	43,480	29.1 %
Age 5 to 9	39,678	26.6 %
Age 10 to 14	40,623	27.2 %
Age 15 to 17	25,500	17.1 %
<b>Total</b>	<b>149,281</b>	

The 2011 Census data compiled by the Office of National Statistics shows that Bury, Rochdale and Oldham have a combined population of 621,656 of which 149,281 (24%) are children under 18 years of age. Of the three local authorities Oldham has the largest percentage of children in its area.

	Total Population	Child Population	
Bury	185,060	41,952	22.7 %
Rochdale	211,699	50,772	24.0 %
Oldham	224,897	56,557	25.1 %
<b>Total</b>	<b>621,656</b>	<b>149,281</b>	<b>24 %</b>

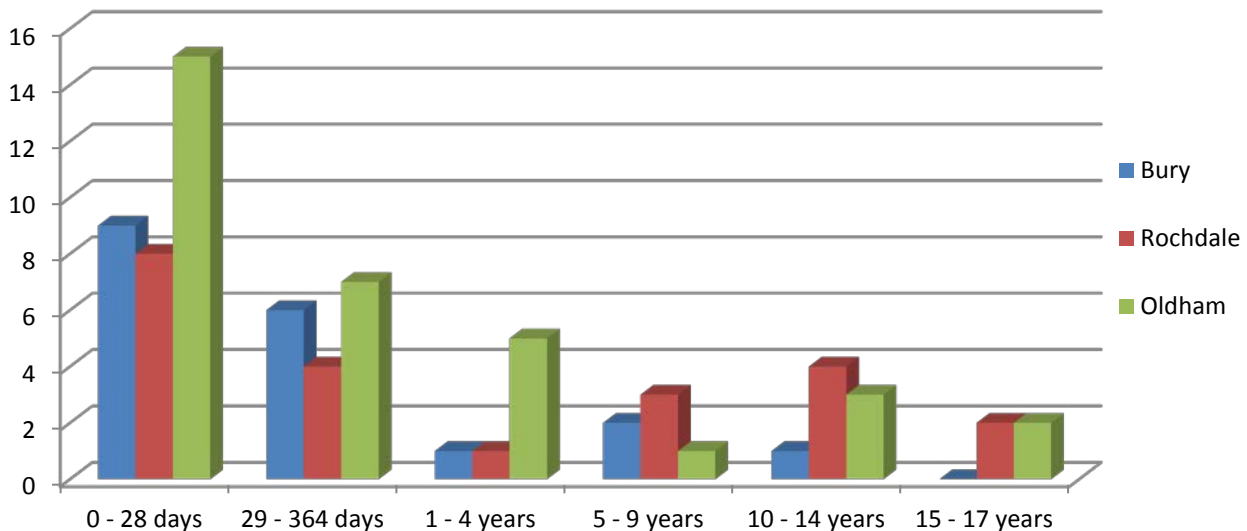
When comparing the 2001 Census and the 2011 Census there has been an increase in the total population across Bury, Rochdale and Oldham by 3.1% from 603,226 to 621,656. Whilst the total population (all ages) has increased the child population (0 – 17 years) has decreased by 2.2 % from 152,695 to 149,281. Of the three local authority's only Oldham saw a slight increase in child population by 0.7% from 56,181 to 56,557.

	2001 Population		2011 Population	
	Child Population	Total Population	Child Population	Total Population
Bury	43,750	180,604	41,952	185,060
Rochdale	52,764	205,360	50,772	211,699
Oldham	56,181	217,262	56,557	224,897
Total	152,695	603,226	149,281	621,656



## 9. Childs Age at Death

The below graph contains information of the 74 child deaths referred to panel from the 1 April 2013 to the 31 March 2014 and provides an overview of the child's age at death.



Age at Death	Bury	Rochdale	Oldham	Total	
0 - 28 days	9	8	15	32	43%
29 - 364 days	6	4	7	17	23%
1 - 4 years	<3	<3	5	7	9%
5 - 9 years	<3	3	<3	6	8%
10 - 14 years	<3	4	3	8	11%
15 - 17 years	0	<3	<3	4	5%
Total	19	22	33	74	100%

0 - 28 days	32	43%
29 - 364 days	17	23%
1 - 4 years	7	9%
5 - 9 years	6	8%
10 - 14 years	8	11%
15 - 17 years	4	5%

All three of the local authorities found the highest number of deaths occurred in neonates (deaths within 28 days of life) with a joint total of 43% (32) of the overall deaths. Another large proportion of the deaths occurred in children aged 29 - 365 days, calculating 23% (17). If we combine the two categories this would indicate that 49 (66%) of the 74 child deaths occurred within the first year of life.

Of the total 409 child death notifications from 1<sup>st</sup> April 2008 to 31<sup>st</sup> March 2014, neonatal deaths make up 43% (175) and children who died between 29 - 365 days make up 22% (91) of the total deaths.

Collating joint data based on the child's year of death and comparing this year on year highlights that both neonates and babies under the age of 1 are those most at risk of reduced infant mortality. These figures may change slightly if in future the panel receives a late notification from previous years. The data for 2014 will be included in the 2014/2015 CDOP Annual Report.

Age by Year of Death	2008	2009	2010	2011	2012	2013	Total	
0 - 28 days	20	31	26	33	29	26	165	42%
29 - 364 days	16	12	15	12	15	19	89	23%
1 - 4 years	10	11	10	9	6	10	56	14%
5 - 9 years	0	3	3	3	<3	7	18	5%
10 - 14 years	3	4	7	5	5	8	32	8%
15 - 17 years	3	4	10	7	4	<3	29	7%
Total	52	65	71	69	61	72	389	100%

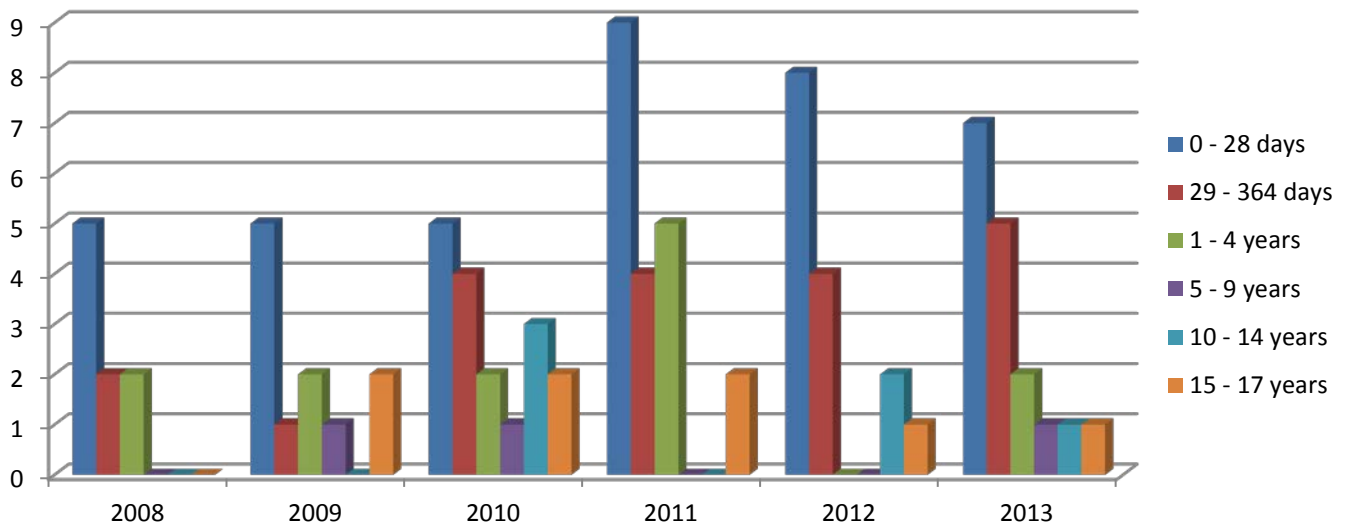
The data above is that of Bury, Rochdale and Oldham only and does not include the 3 out of area cases referred to the panel. Analyse of these cases has been undertaken by the child's CDOP of residence and included in their annual report.

Year on year the highest number of child deaths fall amongst children under the age of 1 as shown below:

2008	36	69%
2009	43	66%
2010	41	57%
2011	45	65%
2012	44	72%
2013	45	62%

Breaking down the data into the three local authorities provides a detailed overview of the number of deaths in each age group across the boroughs. This data is based on the child's year of death.

## Bury



	2008	2009	2010	2011	2012	2013	Total	
0 - 28 days	5	5	5	9	8	7	39	44%
29 - 364 days	<3	<3	4	4	4	5	20	22%
1 - 4 years	<3	<3	<3	5	0	<3	13	15%
5 - 9 years	0	<3	<3	0	0	<3	3	3%
10 - 14 years	0	0	3	0	<3	<3	6	7%
15 - 17 years	0	<3	<3	<3	<3	<3	8	9%
Total	9	11	17	20	15	17	89	100

The largest number of child deaths in Bury occurred in children under the age of 1 totalling 59 (66%) of the 89 deaths. Of the 59 deaths under 1, 39 of (44%) these were neonatal deaths and 20 (22%) died between 28-365 days of life. Another vulnerable age group was identified in children aged 1 – 4 years with 13 (15%) of the 89 deaths.

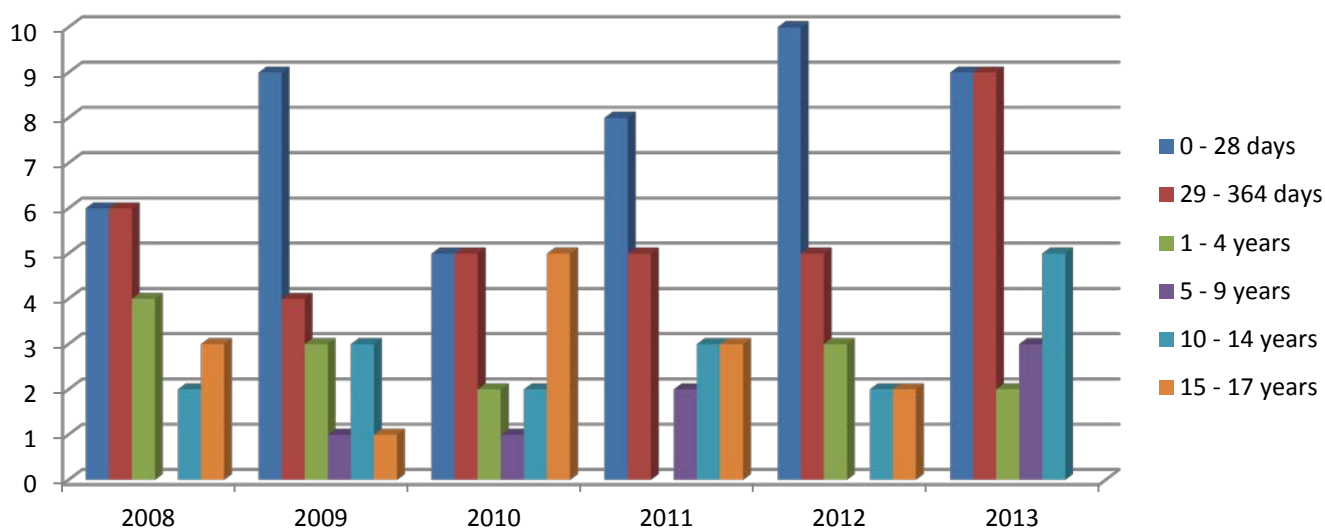
In 2010 there was an increase in the number of child deaths in children aged 10 – 14 years. A number of these children died from life limiting conditions.

Of the three local authorities Bury has the least number of child deaths. From viewing year in year statistics there has been no drastic increase/decrease in specific age groups due to figures being so small that an increase in 1 death can be viewed as much larger percentage but remains insignificant.

The <sup>1</sup>Index of Multiple Deprivation (2010) score gave the local authority a national rank order of 119th most-deprived district out of 326 in England (1 being the most deprived). It would appear that there is an emerging link between the numbers of deaths where children lived within areas of deprivation. Of the three local authorities Bury is the most affluent borough and has much smaller pockets of deprivation in comparison to Rochdale and Oldham. Whilst Bury has the smallest child population (41,952) of the three local authorities, we can assume that a low level of deprivation is one of the reasons why Bury has a smaller number of child deaths in comparison to Oldham and Rochdale.

<sup>1</sup> <sup>1</sup>Department for Communities and Local Government <http://opendatacommunities.org/data/societal-wellbeing/deprivation/imd-rank-la-2010>  
The dataset contains a summary measure of the Index of Multiple Deprivation 2010 at local authority district level. It puts the 326 Local Authority Districts into a rank order based the population weighted average rank of all LSOAs in the LAD. A rank of 1 is the most deprived.

## Rochdale



	2008	2009	2010	2011	2012	2013	Total	
0 - 28 days	6	9	5	8	10	9	47	35%
29 - 364 days	6	4	5	5	5	9	34	26%
1 - 4 years	4	3	<3	0	3	<3	14	11%
5 - 9 years	0	<3	<3	<3	0	3	7	5%
10 - 14 years	<3	3	<3	3	<3	5	17	13%
15 - 17 years	3	<3	5	3	<3	0	14	11%
Total	21	21	20	21	22	28	133	100%

The largest number of child deaths in Rochdale occurred in children under the age of 1 totalling 81 (61%) of the 133 deaths. Of the 81 deaths under 1, 47 (35%) of these were neonatal deaths and 34 (26%) died between 28 -365 days of life.

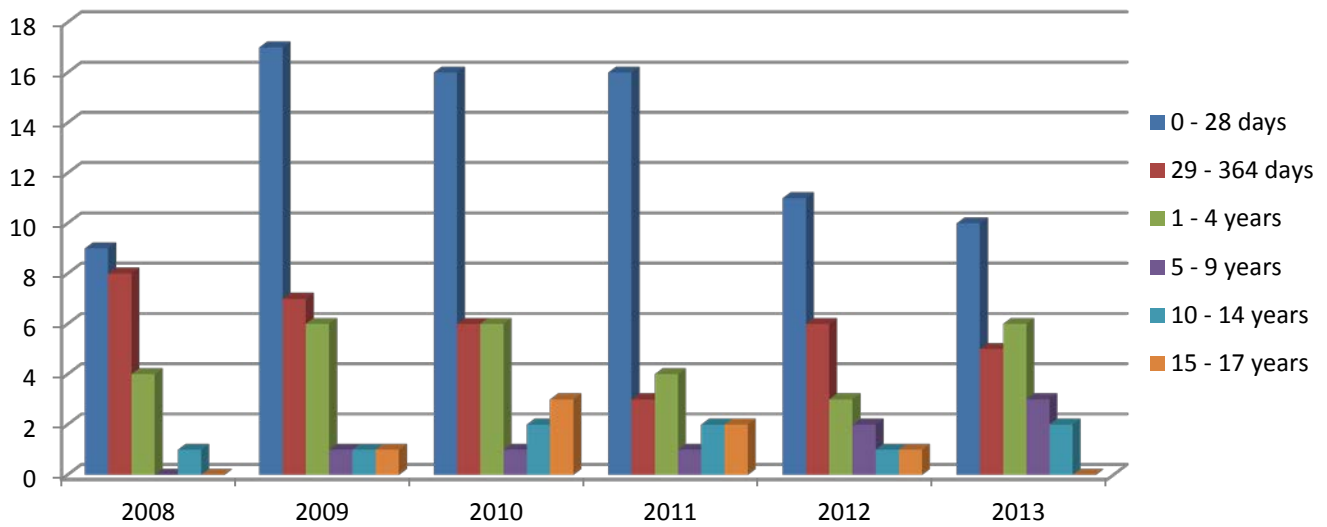
Unlike Bury and Oldham that identified children aged 1-4 years as the second most vulnerable group after under 1s, Rochdale have had slightly more child deaths aged 10 – 14 years (17/13%). Of the total 17 deaths in children aged 10-14 years, the largest number of deaths occurred due to life limiting conditions, 8/47%, and H1N1 Influenza (Swine Flu), 3/18%.

Another age group largely represented are children aged 15 – 17 years. In 2010 the number of child deaths aged 15 - 17 years increased to 5 in comparison to previous years, making up 25% of the total 20 child deaths that year. 3 of these deaths were caused due to life limiting conditions. 2013 saw a decrease in the number of child deaths aged 15 – 17 years reported to CDOP.

Of the total 14 child deaths aged 15-17 years the largest number of deaths occurred due to child with life limiting conditions, 5/36%. A further 3/21% died due to infection and 3/21% following a road traffic collision.

The Index of Multiple Deprivation (2010) score gave the local authority a national rank order of 29th most-deprived district out of 326 in England (1 being the most deprived). Of the 3 boroughs Rochdale is the most deprived local authority and demonstrates a link between the numbers of deaths where children lived within areas of deprivation.

## Oldham



	2008	2009	2010	2011	2012	2013	Total	
0 - 28 days	9	17	16	16	11	10	79	47%
29 - 364 days	8	7	6	3	6	5	35	21%
1 - 4 years	4	6	6	4	3	6	29	17%
5 - 9 years	0	<3	<3	<3	<3	3	8	5%
10 - 14 years	<3	<3	<3	<3	<3	<3	9	5%
15 - 17 years	0	<3	3	<3	<3	0	7	4%
Total	22	33	34	28	24	26	167	100%

The largest number of child deaths in Oldham occurred in children under the age of 1 totalling 114 (68%) of the 167 deaths. Of the 167 deaths under 1, 79 (47%) of these were neonatal deaths and 35 (21%) died between 28 -365 days of life.

Of the 3 boroughs Oldham has the largest child population (56,557/25%) and has received the most child death notifications in total. There appears to be no significant increase/decrease in figures year on year in any particular age group. Oldham has received nearly double the amount of child deaths in comparison to Bury. In comparison to Rochdale Oldham has received fewer child death notifications aged 10 – 14 years and 15 – 17 years.

The Index of Multiple Deprivation (2010) score gave the local authority a national rank order of 46<sup>th</sup> most-deprived district out of 326 in England (1 being the most deprived).

## 10. Child Deaths Under 1

Between 1 April 2013 and 31 March 2014 child deaths under the age of 1 (excluding neonates) made up 17 (23%) of the 74 notifications. Of the 17 child deaths the main causes of death were categorised as:

Sudden unexpected, unexplained death	7	41%
Perinatal/neonatal event	5	29%
Chromosomal, genetic and congenital anomalies	3	18%

Of the 17 deaths aged 29 days to 364 days, 3 of these were female (18%) and 14 male (82%). 10 children were from the BME community (59%) and 7 of the ethnicity White/White British (41%).

The highest number of deaths occurred where the child was resident in quintile 1 (most deprived area), making up 11 (65%) of the total 17 deaths. A further 3 (18%) deaths occurred in quintile 2 (2nd Most Deprived). Combining the two areas of deprivation highlights a total of 14 (83%) out of 17 deaths which occurred where the child was resident in a deprived area.

### Neonatal Deaths

There are a number of contributing risk factors in neonatal deaths which include:

1. Smoking during pregnancy
2. Prematurity & birth weight
3. Multiple pregnancies

#### 1. Smoking During Pregnancy

<sup>2</sup>Mothers that smoke during pregnancy are exposing their unborn baby to harmful gases like carbon monoxide and other damaging chemicals. There are a number of health risks when smoking during pregnancy which can include:

- increased complications in pregnancy
- less likely to have a healthier pregnancy and a healthier baby in comparison to those who do not smoke
- increased risk of stillbirth
- the baby is more likely to be born early and suffer additional breathing, feeding and health problems that often go with being premature
- the baby is more likely to be born underweight: babies of women who smoke are, on average, 200g (about 8oz) lighter than other babies, which can cause problems during and after labour, for example they are more likely to have a problem keeping warm and are more prone to infection
- increased risk of cot death
- children whose parents smoke are more likely to suffer from asthma and other more serious illnesses that may need hospital treatment.

<sup>3</sup>A study carried out by [University College London](http://www.ucl.ac.uk) researchers found that smoking during pregnancy increases the risk of birth defects, such as club foot and missing limbs. The report is based on a systematic review which assessed previous research on smoking during pregnancy to determine the risks of birth defects. It found that the risk of various birth defects increased for mothers who smoked, with the odds rising from between 9% and 50% for different abnormalities. The annual incidence of these sorts of defect is around 3 to 5% of births in the UK. Overall, this was a well-conducted study, and its findings are convincing evidence that smoking increases the risk of some birth defects.

<sup>2</sup> NHS <http://www.nhs.uk/conditions/pregnancy-and-baby/pages/smoking-pregnant.aspx>

<sup>3</sup> NHS <http://www.nhs.uk/news/2011/07/July/Pages/smoking-in-pregnancy-link-to-birth-defects.aspx>

	Yes	No	Not Known	Total
Bury	<3	8	0	9
Rochdale	<3	6	0	8
Oldham	0	12	3	15
Total	3	26	3	32

Of the 32 neonatal deaths, Mothers smoking status was recorded in 29 cases (91%) and 3 were unknown (9%). Of the 29 deaths where Mother smoking status was recorded, 3 Mothers (10%) self-declared that they smoked during pregnancy and 26 Mothers (90%) stated they did not.

Due to the health risks linked to smoking in pregnancy all CDOPs across Greater Manchester have agreed that for premature deaths, where Mother smoked during pregnancy, these would be categorised as having modifiable factors. (See Section 7 Cases Closed Between 1 April 2013 - 31 March 2014 for preventability).

The NHS continues to work with Mothers that smoke during pregnancy to highlight the health risks to both Mother and baby. When a Mother declares at booking that she is a smoker, she is offered a referral to smoking cessation. This requires consent from the Mother and can be refused. Information is requested about other household members who smoke and advice is also provided to them about the benefits of stopping smoking/cessation. Parents are informed about the risks of smoking during pregnancy and once the baby is born the midwife will go through safe sleeping arrangements which incorporates smoking. Information leaflets are provided to parents as well as verbal advice both before and after birth about the NHS Pregnancy Smoking Helpline.

## 2. Prematurity and Birth Weight

<sup>4</sup>About one baby in every 13 will be born prematurely. The chances of survival depend on many factors including the stage of the pregnancy, birth weight, inherited abnormalities, condition at birth and presence or absence of infection.

The NHS determines births at the gestation of 37 weeks and over as full term pregnancies. Any delivery under 37 weeks gestation is classified as a premature birth. Babies delivered under 26 weeks gestation are classified as extremely premature births.

<sup>5</sup>Babies born extremely prematurely have very immature organs. They are at increased risk of problems in later childhood even if they survive the neonatal period. These are some of the potential problems:

- Damage to their brain, such as cerebral parenchymal cysts (small “holes” in the brain) and hydrocephalus (too much fluid in the brain). These changes can cause cerebral palsy and/or learning difficulties.
- Damage to their eyes (retinopathy), which may affect their vision
- Hearing problems
- Damage to the lungs (chronic lung disease) causing breathing problems
- Problems with feeding and long term growth

<sup>4</sup> NHS <http://www.nhs.uk/conditions/pregnancy-and-baby/pages/premature-early-labour.aspx#close>

<sup>5</sup> SUHT NHS Information:

<http://www.uhs.nhs.uk/Media/Controlleddocuments/Patientinformation/Pregnancyandbirth/Havinganextremelyprematurebaby-patientinformation.pdf>

<sup>6</sup>Babies who are born extremely premature have an increased rate of infant mortality:



25 weeks gestation: 6 - 7 in 10 survive, of whom 4 in 10 have moderate to severe disability  
 24 weeks gestation: 4-5 in 10 survive, of whom half have moderate to severe disability  
 23 weeks gestation: 2-3 in 10 survive, of whom two thirds have moderate to severe disability  
 22 weeks gestation: Only 1 in 100 babies survive with likely severe disability

The below data is based on the 32 neonatal deaths referred to the CDOP between 1 April 2013 to 31 March 2014. Of the 32 neonatal deaths, 21 (66%) were born prematurely and 11 (34%) were born full term.

	Bury	Rochdale	Oldham	Total	
Extremely Premature (<26 weeks)	<3	4	7	13	41%
Premature (26 weeks to <37 weeks)	4	<3	3	8	25%
Full Term (37+ weeks)	3	3	5	11	34%

Low birth weight is defined as a birth weight of a live born infant of less than 2,500 grams (5.5 pounds) regardless of gestational age. This is another contributing factor for neonatal deaths as the earlier the gestation the lower the birth weight of the infant. The below data is based on the 32 neonatal deaths referred to panel from 1 April 2013 to 31 March 2014. Of the 32 neonatal deaths, birth weight was recorded in 31 of the cases.

	Bury	Rochdale	Oldham	Total	
Low Birth Weight <2500 Grams	5	5	10	20	65%
2500+ Grams	3	3	5	11	35%

Of the 31 neonatal deaths where birth weight was recorded 20 of these (65%) were born with a low birth weight. Of the 20 cases recorded as having low birth weight 18 of these were born prematurely.

<sup>6</sup> The information in these charts comes from two large studies (EPICURE 1 in 1995 and EPICURE 2 in 2006), which assessed the outcome of large groups of babies that were born during these weeks of pregnancy in the U.K.  
<http://www.uhs.nhs.uk/Media/Controlleddocuments/Patientinformation/Pregnancyandbirth/Havinganextremelyprematurebaby-patientinformation.pdf>



### 3. Multiple Pregnancies

<sup>7</sup>Many twins and triplets are born prematurely. The average delivery date for twins is 37 weeks and 33 weeks for triplets. Fewer than half of all twin pregnancies last beyond 37 weeks, and only 1.5% of triplet pregnancies go beyond this stage.

<sup>8</sup>There are a number of risks involving multiple pregnancies:

- half of all twins are born prematurely (before 37 weeks) and have a low birth weight of under 2.5kg (5.5lb); triplets have a 90% chance of being born prematurely and of having a low birth weight
- the risk of death for premature babies around the week of birth is five times higher for twins and nine times higher for triplets than single babies

	Bury	Rochdale	Oldham	Total	
Single	8	5	10	23	72%
Twin	<3	3	<3	6	19%
Triplet	0	0	3	3	9%

Of the 32 neonatal deaths 6 (19%) of these were twin pregnancies, 2 pregnancies accounting for 4 of the deaths. Of the 2 remaining pregnancies the other twins remain alive and well.

---

<sup>7</sup> NHS: <http://www.nhs.uk/conditions/pregnancy-and-baby/pages/premature-early-labour.aspx#close>

<sup>8</sup> NHS <http://www.nhs.uk/conditions/pregnancy-and-baby/pages/twins-healthy-multiple-pregnancy.aspx>

## 11. Gender across the Local Authority

The below table provides information from the Office of National Statistics (ONS) 2011 Census, regarding gender across the child population for children aged 0 – 17 years.

	Bury		Rochdale		Oldham		Total	
Male	21,584	51%	26,061	51%	28,799	51%	76,547	51%
Female	20,368	49%	24,711	49%	27,758	49%	72,934	49%
Total	41,952	100%	50,772	100%	56,557	100%	149,481	100%

Each of the 3 local authorities' child population has a slightly higher percentage of males (51%) than females (49%).

### Life Expectancy

<sup>9</sup>The below table provides information from the ONS release: Life expectancy at birth and at age 65 by local areas in England and Wales, 2010-12

	Male	Rank	Female	Rank
Bury	78.0	270	81.0	326
Rochdale	76.8	329	80.8	331
Oldham	77.1	322	81.1	323
Greater Manchester	77.3	-	81.3	-
North West	77.6	-	81.6	-
England	79.2	-	83.0	-

The ranking of local authorities is based on 1 being the highest and 346 being the lowest. On average, life expectancy at birth increased across all local areas in England and Wales by 1.3 years for males and 1.0 year for females between 2006–08 and 2010–12. The distribution of life expectancy across England was characterised by a north-south divide, with people in local areas in the north generally living shorter lives than those in the south.

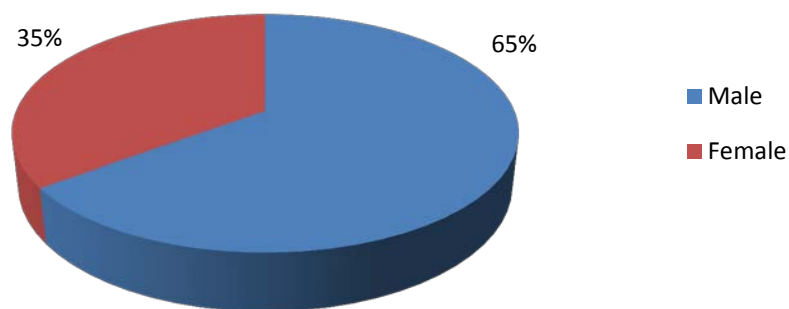
<sup>10</sup>A newborn baby boy could expect to live 78.9 years and a newborn baby girl 82.7 years if mortality rates remain the same as they were in the United Kingdom (UK) in 2011 - 2013 throughout their lives. Life expectancy at birth has increased by 6.3 hours per day since 1980 - 1982 for males, and by 4.6 hours per day for females in the UK. The most common age at death was 86 for men and 89 for women in 2011-2013. In 2011 - 2013 a man in the UK aged 65 had an average further 18.3 years of life remaining and a woman 20.8 years.

<sup>9</sup> ONS - Life expectancy at birth and at age 65 by local areas in England and Wales, 2010-12  
<http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-326676>

<sup>10</sup> ONS - National Life Tables, United Kingdom, 2011-2013 <http://www.ons.gov.uk/ons/rel/lifetables/national-life-tables/2011-2013/stb-uk-2011-2013.html>

## 12. Gender of Child Deaths

The data below is based on the 74 child death notifications received from the 1 April 2013 to 31 March 2014. Of the 74 child death notifications 48 (65%) of these were male and 26 (35%) female.



	Male		Female	
Bury	12	63%	7	37%
Rochdale	16	73%	6	27%
Oldham	20	61%	13	39%
Total	48	65%	26	35%

Breaking the figures down into each local authority indicates that in each borough there were a higher number of male child deaths. In Rochdale there was more than double the amount of female child deaths to male.

The difference in the percentage increase of female to male deaths:

Bury	42%
Rochdale	63%
Oldham	35%

Reviewing the child's gender by the year of death provides a more accurate overview when analysing the increase/decrease of gender. The data below is based on the year the death occurred. Of the 389 child deaths which occurred between 2008 – 2013 gender was recorded in 388 cases. The data for 2014 will be included in the 2014/2015 CDOP Annual Report.

	Bury		Rochdale		Oldham	
	Female	Male	Female	Male	Female	Male
2008	3	6	12	9	8	14
2009	6	5	8	13	13	20
2010	8	9	8	12	9	25
2011	10	10	9	12	11	17
2012	8	7	9	12	13	11
2013	5	12	8	20	14	12
Total	40	49	54	78	68	99
	45%	55%	41%	59%	41%	59%

Reviewing the statistics by the child's year of death highlights that in Bury in 2009 and 2012 there were more female child deaths than male. There was also a 50/50 split between male and female death in 2011. In 2008 Rochdale saw a higher number of female child deaths to male. In Oldham there was more female deaths in comparison to male in 2012 and 2013. It's important to note that as figures are small that one death could alter these statistics.

From 2008 to 2013 the total figure indicates that overall there have been more child deaths in males (226/58%) than females (162/42%).

	Female		Male		Total
2008	23	44%	29	56%	52
2009	27	42%	38	58%	65
2010	25	35%	46	65%	71
2011	30	43%	39	57%	69
2012	30	50%	30	50%	60
2013	27	38%	44	62%	71
Total	162	42%	226	58%	388

## 13. Ethnicity across the Local Authorities

The below table provides information from the Office of National Statistics 2011 Census, regarding ethnicity for the child population of children aged 0 – 17 years.

Ethnicity		England	North West	Greater Manchester	Bury	Rochdale	Oldham	CDOP Total	
White	White	English/Welsh/Scottish/ Northern Irish/British	8,442,330	1,235,092	436,852	33,447	35,099	35,345	103,891
		Irish	33,889	3,574	1,980	123	89	79	291
		Gypsy or Irish Traveller	19,615	1,388	509	18	62	23	103
		Other White	407,479	26,630	12,105	969	780	451	2,200
		<b>White: Total</b>	<b>8,903,313</b>	<b>1,266,684</b>	<b>451,446</b>	<b>34,557</b>	<b>36,030</b>	<b>35,898</b>	<b>106,485</b>
BME Community	Mixed/multiple ethnic group	White and Black Caribbean	206,044	17,693	11,250	663	445	983	2,091
		White and Black African	85,284	8,951	4,948	226	279	239	744
		White and Asian	171,250	16,080	8,402	617	743	714	2,074
		Other Mixed	127,439	10,219	5,663	283	271	281	835
		<b>Mixed/multiple ethnic group: Total</b>	<b>590,017</b>	<b>52,943</b>	<b>30,263</b>	<b>1,789</b>	<b>1,738</b>	<b>2,217</b>	<b>5,744</b>
	Asian/Asian British	Indian	298,950	29,506	13,592	345	279	297	921
		Pakistani	403,323	70,100	47,524	3,442	8,268	8,983	20,693
		Bangladeshi	167,009	19,445	14,451	122	1,855	7,433	9,410
		Chinese	59,108	8,367	4,465	248	251	165	664
		Other Asian	207,903	12,951	8,245	495	1,062	657	2,214
		<b>Asian/Asian British: Total</b>	<b>1,136,293</b>	<b>140,369</b>	<b>88,277</b>	<b>4,652</b>	<b>11,715</b>	<b>17,535</b>	<b>33,902</b>
	Black/African/Caribbean/Black	African	327,168	19,520	15,502	400	850	580	1,830
		Caribbean	119,017	3,476	2,884	77	33	75	185
		Other Black	116,148	6,251	4,877	62	165	113	340
		<b>Black/African/Caribbean/Black British: Total</b>	<b>562,333</b>	<b>29,247</b>	<b>23,263</b>	<b>539</b>	<b>1,048</b>	<b>768</b>	<b>2,355</b>
	Other ethnic group	Arab	68,840	8,230	5,329	168	118	39	325
		Any other ethnic group	76,164	4,566	3,046	247	123	100	470
		<b>Other ethnic group: Total</b>	<b>145,004</b>	<b>12,796</b>	<b>8,375</b>	<b>415</b>	<b>241</b>	<b>139</b>	<b>795</b>
	<b>Total: All Ethnic Groups</b>		<b>11,336,960</b>	<b>1,502,039</b>	<b>601,624</b>	<b>41,952</b>	<b>50,772</b>	<b>56,557</b>	<b>149,281</b>

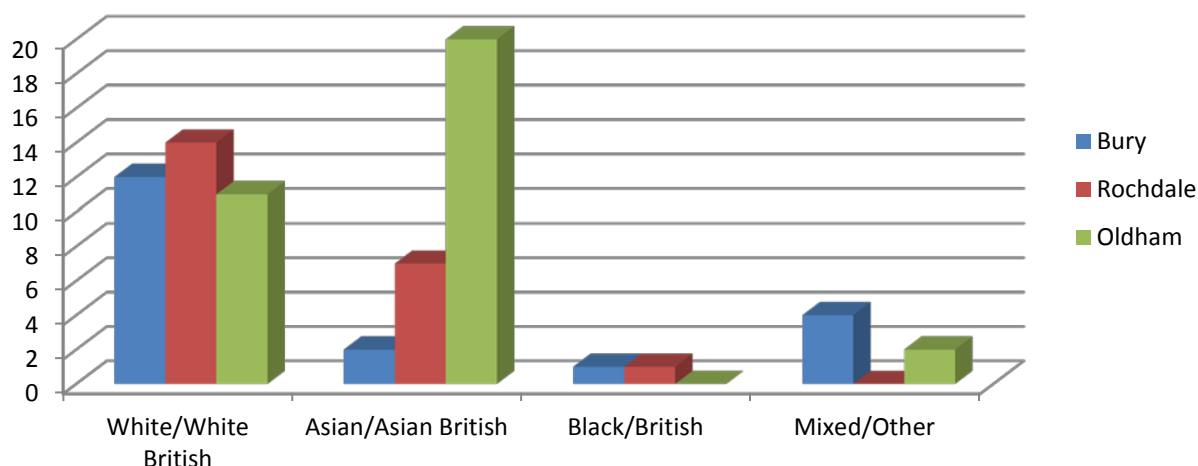
In all three of the local authorities child population the white community is the most represented with a total of 71.% (106,485) of the CDOPs joint population. The BME community makes up 29% (42,796) of the joint population.

Bury BME	7,395	18 %
Rochdale BME	14,742	29 %
Oldham BME	20,659	37 %
Greater Manchester BME	150,178	25 %
North West BME	235,355	16 %
England BME	2,433,647	22 %

Of the three local authorities Oldham has the largest proportion of children from the BME community with 37% (20,659) of its child population. In comparison to the national and regional percentages Oldham and Rochdale have a higher BME community in comparison to the national average. Of Bury, Rochdale and Oldham's BME community the Pakistani community is the most prevalent in all three local authorities. In Bury the Pakistani community makes up 3,442 (47% of Bury's child BME community/8% of Bury's total child population), Rochdale 8,268 (56% of Rochdale's child BME community/16% of Rochdale's total child population) and Oldham 8,983 (44% of Oldham's BME community/16% of Oldham's total child population).

## 14. Ethnicity of Child Deaths

The below data is based on the 74 child death notifications received between 1 April 2013 to 31 March 2014. Of the 74 child death notifications received there was a 50/50 split in the number of child deaths of White/White British ethnicity 37 (50%) and children from the Black Minority Ethnic (BME) community 37 (50%) also.



	Bury		Rochdale		Oldham		Total	
White/White British	12	63%	14	64%	11	33%	37	50%
Asian/Asian British	<3	11%	7	32%	20	61%	29	39%
Black/British	<3	5%	<3	5%	0	0%	<3	3%
Mixed/Other	4	21%	0	0%	<3	6%	6	8%
<b>Total</b>	<b>19</b>	<b>100%</b>	<b>22</b>	<b>100%</b>	<b>33</b>	<b>100%</b>	<b>74</b>	<b>100%</b>

The figures below show that overall Oldham also has a much larger percentage of child deaths from the BME community. Breaking the figures down into specific ethnicities within each local authority identifies that Oldham has a much higher percentage of child deaths from the Pakistani community in comparison to Bury and Rochdale.

Bury	White/White British	12 / 63%	Black Minority Ethnic	7 / 37%
Rochdale	White/White British	14 / 64%	Black Minority Ethnic	8 / 36%
Oldham	White/White British	11 / 33%	Black Minority Ethnic	22 / 66%

	Bury		Rochdale		Oldham		Total	
Asian or Asian British: Bangladeshi	0	0%	0	0%	6	18%	6	8%
Asian or Asian British: Pakistani	<3	11%	7	32%	14	42%	23	31%
Black: African	<3	5%	<3	5%	0	0%	<3	3%
Mixed: White & Asian	0	0%	0	0%	<3	3%	<3	1%
Mixed: White & Black Caribbean	<3	11%	0	0%	0	0%	<3	3%
Mixed: White & Black African	0	0%	0	0%	<3	3%	<3	1%
White English/Welsh/Scottish/N Irish/British	10	53%	14	64%	10	30%	34	46%
White: Any Other White background	<3	11%	0	0%	<3	3%	3	4%
Other: Any other	<3	11%	0	0%	0	0%	<3	3%
<b>Total</b>	<b>19</b>	<b>100%</b>	<b>22</b>	<b>100%</b>	<b>33</b>	<b>100%</b>	<b>74</b>	<b>100%</b>

When reviewing the White/White British child population (age 0 – 17 years) and comparing this to the number of deaths it would appear that this group are underrepresented.

Bury:	White/White British Child Population	34,557 / 82%	Deaths	12 / 63 %
Rochdale:	White/White British Child Population	36,030 / 70%	Deaths	14 / 64%
Oldham:	White/White British Child Population	35,898 / 64%	Deaths	11 / 33%

Reviewing the percentage of the BME child population in comparison to the number of BME child deaths it would appear that this group is overrepresented.

Bury:	Black Minority Ethnic Child Population	7,395 / 18%	Deaths	7 / 37%
Rochdale:	Black Minority Ethnic Child Population	14,742 / 29%	Deaths	8 / 36%
Oldham:	Black Minority Ethnic Child Population	20,659 / 37%	Deaths	22 / 66%

Of the 37 BME child deaths across Bury, Rochdale and Oldham, 23 of these were of Pakistani heritage totalling 62% of the BME child deaths. Child deaths of Bangladeshi heritage accounted for 16% (6) of the total BME deaths, making these two ethnic groups the most prevalent within the BME community. Reviewing the nature of the 37 BME deaths highlights:

- the largest proportion of deaths occurred in children under the age of 1 totalling 27 / 73% (17, 0–28 days and 10, 29–364 days)
- 27 (73%) children were resident in quintile 1 (most deprived area) and
- the CDOP categorised consanguinity as a contributing factor in that in 9 (24%) of the child deaths (see consanguinity section for more information)

Comparing statistics from previous annual reports highlights, in cases where ethnicity was recorded there was a higher percentage of child deaths within the BME community in 2009/10. From 2010/11 onwards there was a higher percentage of deaths in children of White/White British ethnicity.

	White/White British		BME community	
2013/14	37	50%	37	50%
2012/13	37	58%	27	42%
2011/12	43	54%	37	46%
2010/11	40	59%	28	41%
2009/10	20	43%	26	57%

# 15. Consanguinity

## Genetics and Consanguinity

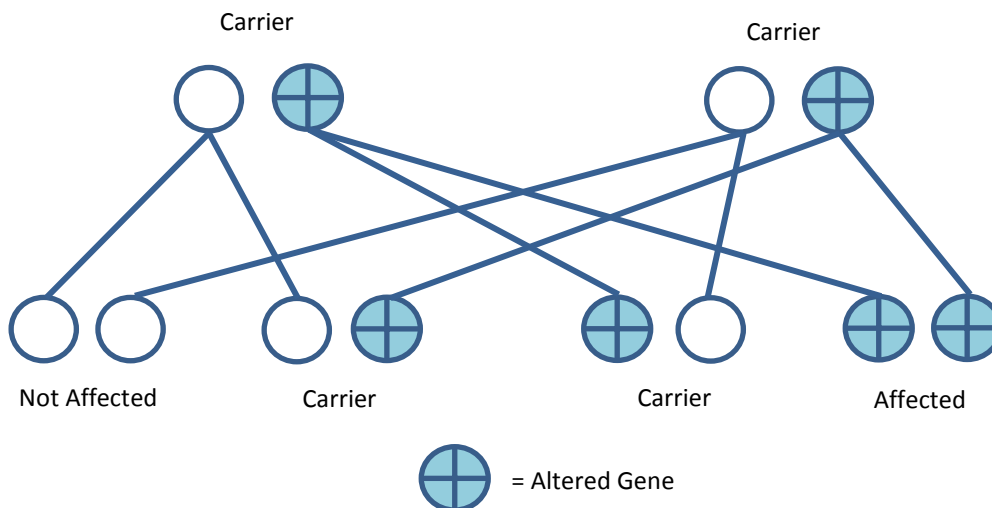
<sup>11</sup>Consanguinity refers to a relationship in which a couple are 'blood' relatives, i.e. they share a common ancestor. An example is a couple who are first cousins. Consanguinity is common in many cultures and most prevalent in the Asian community. Consanguinity is important because it increases the risk of genetic disorders called autosomal recessive disorders.

These are disorders which only occur if a child has a change (known as a mutation) in both copies of a particular gene. Because genes come in pairs it often doesn't matter if there one changed copy because the other copy is normal and can compensate for the changed gene. A parent with one changed copy is therefore called a 'healthy carrier'. For parent to have an autosomal recessive disorder he/she must have two changed copies of a particular gene.

For example, an individual with cystic fibrosis (a common autosomal recessive disorder in Europe) has two changed copies of the cystic fibrosis gene. Because one copy of each gene comes from Mother and one from Father, both parents of an individual with an autosomal recessive condition must have at least one changed copy of the gene causing the disorder. Therefore if two carriers have a child together there is a risk that their child could be affected by that disorder.

Parents, who are both healthy carriers of, for example cystic fibrosis, there are several possibilities for each of their children:

- A 1 in 4 (25%) chance that the child could be affected by cystic fibrosis.
- A 1 in 2 (50%) chance that the child could be a healthy carrier.
- A 1 in 4 (25%) chance that the child could have 2 normal copies of the cystic fibrosis gene and therefore would not be a carrier or affected.



With every pregnancy this chance stays the same, a bit like tossing a coin or throwing a dice. To put things into context unrelated parents have a risk of about 2 in 100 (2%) of having a child with a severe/lethal abnormality. Parents who are first cousins have an additional risk of about 3 in 100 (3%), giving them a total risk of about 5 in 100 (5%). Parents who are first cousins once removed or 2nd cousins have an additional risk of about 1 in 100 (1%) and therefore a total risk of about 3 in 100 (3%).

<sup>11</sup> <http://www.scotgen.org.uk/documents/Consanguinity.pdf>



This means that when there is no family history of a recessive disorder, most children of first cousins and more distant relatives will be healthy (95% for first cousins, and 97% for first cousins once removed and second cousins). However, certain couples may be more closely related if there is a family tradition of cousin marriages going back generations. In this situation, the couple will have a higher risk of having a child with problems.

About half or 50% of these severe abnormalities are thought to be detectable by specialised ultrasound scanning at around 18 weeks of pregnancy. These scans can be easily arranged by a midwife, genetics department or GP.

## Consanguinity and Child Deaths

Of the 74 child death notifications in 2013/14 consanguinity was recorded in 56 (76%) of the cases. In 41 cases parents stated that they were not related. Of the 18 cases where parent's relationship was recorded as not known in 13 of the deaths consanguinity would not have been a contributing factor linked to the cause of death. Although there were 5 cases where consanguinity was not known these children died due to conditions such as End Stage Cystic Fibrosis, Batters Disease, Sandhoff's Syndrome and Multiple Congenital Abnormalities which are potentially inherited conditions.

Of the 56 child deaths where consanguinity was recorded 15 families self-declared that they were in a consanguineous relationship. Of the 15 cases where it was recorded that Mother and Father were related 10 of these deaths were directly linked to parents being first cousins making up 14% of the total 74 deaths in 2013/14.

- All 10 of the children were of Pakistani heritage.
- Of the total 74 child deaths 37 (50%) of these were from the BME community.
- Of the 37 BME deaths, consanguinity was relevant and directly linked to 27% (10) of the child deaths.
- 5 of the 10 children (50%) died before the age of 5.
- The highest number of deaths linked to consanguinity occurred in Oldham (4/40%) and Rochdale (4/40%).
- 8 of the 10 families lived within areas of deprivation (quintile 1 and 2).
- There was a 50/50 split in gender with 5 male and 5 female deaths

In 5 of the 10 families, siblings have also been diagnosed with the same inherited life limiting condition and/or there has been a previous death of a sibling. Some of these inherited conditions include:

- Canavan's disease
- Hypoplastic cerebellum, Tracheobronchomalacia
- Epidermolysis Bullosa (treated)
- Metachronic Leucodystrophy
- Batters Disease
- Neuro degenerative disorder (type undefined)
- I-Cell Disease
- Neurodegenerative disorder - severe scoliosis
- Multiple Congenital Anomalies

In many of the consanguineous deaths the final event contributing to the death has been infection. The child's underlying congenital abnormality makes them more vulnerable and susceptible to forms of infection such as Bronchopneumonia and Sepsis. Once the child has contracted a form of infection, due to the complexity of some of the above inherited conditions the child's immune system can be compromised making it much harder for the body to fight off the infection and recover ultimately contributing to the death.

## Consanguinity and the Associated Health Risks

Following the CDOP Annual Report and the links between cousin marriage and the increased risk of autosomal recessive disorders, in 2011 the Oldham Local Safeguarding Children Board (LSCB) created the Oldham Consanguinity Task and Finish Group. The group was established to review data and look at raising awareness of the associated health risks in the community.

In June 2012 Oldham LSCB held a training event for medical professionals to encourage staff to raise awareness of the potential health risks for families to make informed decisions. It was highlighted that parents who are in a relationship/married to a relative can seek further advice from their GP who may then refer them onto St Mary's Genetic Service for genetic counselling. The information was well received and good feedback obtained from attendees.

The task group looked at various methods of communication to raise awareness with the public. Discussions were held with Public Health to take the lead on consanguinity and a report detailing the next steps forward was presented to the LSCB and Health and Wellbeing Board. The report aims to develop a preventative approach to reduce the numbers of infant deaths and severely disabled children resulting from inherited conditions. It felt good practice to raise awareness around the highly sensitive issue of consanguineous marriages and making families aware of the associated health risks to ensure that they have received information to make informed decisions.

At present the GP/hospital may refer a family to Saint Mary's Genetic Counselling Service where a genetics counsellor works one day a week in Oldham. However they do not have the capacity to undertake any preventative work or general awareness raising within the community.

Oldham LSCBs consanguinity report was presented to the Health and Wellbeing Board to look at the next steps forward to increase capacity and continue working with families who are most at risk and to raise awareness within the community by providing information in college settings regarding the associated health risks.

Oldham LSCB wishes to implement the following proposal:

1. Targeted work to raise awareness among communities at risk. This needs to result in people understanding that, if there is a family history which raises concerns, they should seek specialist advice. The aim is to ensure that members of the public understand the associated health risks linked to consanguineous relationships to make informed decisions before considering marriage
2. Raising awareness amongst front-line health professionals about the issue enabling them to contribute to the awareness raising, provide the appropriate information and initiate referrals where needed
3. Increasing the capacity of the Saint Mary's service to provide genetic counselling, and to undertake community outreach work.

Calculating the cost implications and impact on the health service is difficult to estimate as every condition varies and requires various sources of treatment and care depending on the child's diagnosis, the severity of their condition and the life expectancy of the child.

At present Oldham Public Health have taken the lead and the report is to be presented to the Integrated Commissioning Partnerships (ICP) to discuss resources to fund and employ a specialist geneticist post who can carry out the proposal.

## How does Consanguinity affect the Population?

Although the CDOP reviews the number of child deaths across Bury, Rochdale and Oldham aged 0 – 17 years, the panel does not collate data relating to terminations of pregnancy, stillbirths and miscarriages. Whilst the Oldham Consanguinity Task Group reviewed the number of child deaths linked to consanguinity, the group also identified the increased risk of stillbirths, miscarriages and children with disabilities.

In November 2014 Bury, Rochdale and Oldham Children with Disabilities Team submitted statistics to the CDOP in relation to the ethnicity of children currently open to the service.

Ethnicity		Oldham		Bury		Rochdale		Total	
White	English/Welsh/Scottish/Northern Irish/British	114	54%	152	69%	247	64%	513	63%
	White: Any Other White background	6	3%	3	1%	4	1%	13	2%
Mixed/multiple ethnic group	White and Black Caribbean	4	2%	<3	1%	0	0%	6	1%
	White and Black African	0	0%	0	0%	<3	0%	<3	0%
	White and Asian	<3	0%	5	2%	8	2%	14	2%
	Other Mixed/Mixed Not Known	6	3%	<3	1%	6	2%	14	2%
Asian/Asian British	Indian	<3	1%	<3	1%	0	0%	4	0%
	Pakistani	58	27%	29	13%	69	18%	156	19%
	Bangladeshi	17	8%	0	0%	6	2%	23	3%
	Chinese	0	0%	<3	0%	0	0%	<3	0%
	Other Asian	0	0%	10	5%	18	5%	28	3%
Black/African/Caribbean/Black British	African	0	0%	<3	1%	7	2%	9	1%
	Caribbean	0	0%	0	0%	0	0%	0	0%
	Other Black	0	0%	7	3%	<3	1%	9	1%
Other ethnic group	Any other ethnic group	0	0%	4	2%	14	4%	18	2%
	Not Known	4	2%	<3	1%	3	1%	9	1%
Total		212	100%	221	100%	385	100%	818	100

## Bury

Bury's child population is made up of 82% White/White British and 18% Black Minority Ethnic. Of the three local authorities Bury's statistics show that they have the fewest number of children with disabilities from the BME community. This is expected when comparing the child population across the three boroughs, with Bury having the smallest percentage of children from the BME community. Reviewing Bury's statistics found that children with disabilities from the BME community were overrepresented with 30% (66) in comparison to the BME child population of 18%.

Child Population		Child with Disabilities		
White/White British	82%	White/White British	155	70%
Black Minority Ethnic	18%	Black Minority Ethnic	66	30%

In Bury the most prevalent ethnic group within the BME child population are children from the Pakistani community (3,442). It would appear that children of Pakistani heritage who represent 8% (3,442) of the child population are overrepresented with 13% (58) of children with disabilities.

## Rochdale

Rochdale's child population is made up of 71% White/White British and 29% Black Minority Ethnic. Reviewing Rochdale's statistics found that children with disabilities from the BME community were overrepresented with 35% (134) in comparison to the BME child population of 29%.

Child Population		Child with Disabilities		
White/White British	71%	White/White British	251	65%
Black Minority Ethnic	29%	Black Minority Ethnic	134	35%

In Rochdale the most prevalent ethnic group within the BME child population are children from the Pakistani community (8,268). It would appear that children of Pakistani heritage who represent 16% (8,268) of the child population are slightly overrepresented with 18% (69) of children with disabilities.

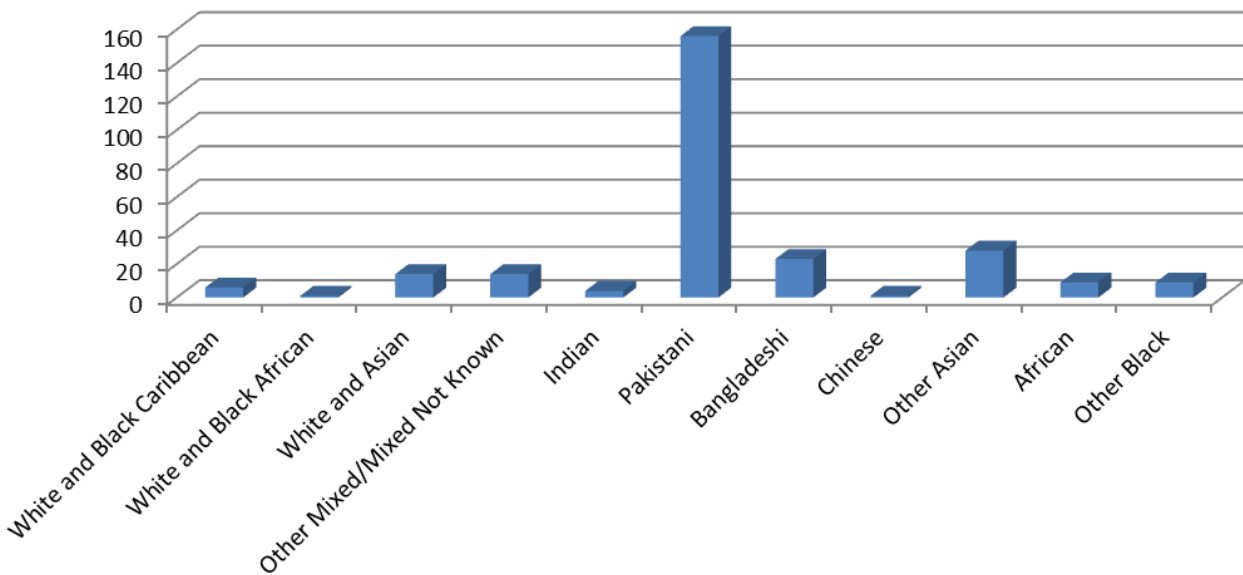
## Oldham

Oldham’s child population is made up of 63% White/White British and 37% Black Minority Ethnic. Reviewing Oldham’s statistics found that children with disabilities from the BME community were overrepresented with 43% (92) in comparison to the BME child population of 37%.

Child Population		Child with Disabilities		
White/White British	63%	White/White British	120	57%
Black Minority Ethnic	37%	Black Minority Ethnic	92	43%

In Oldham the two most prevalent ethnic groups within the BME child population are Pakistani (8,983) and Bangladeshi (7,433). Children of Bangladeshi heritage represent 13% of the child population and are underrepresented with 8% (17) of children with disabilities. Children of Pakistani heritage who represent 16% (8983) of the child population are overrepresented with 27% (58) of children with disabilities. Over the years CDOP has identified that consanguineous relationships are mostly practiced within the South Asian community and most common amongst families of Pakistani heritage.

## Consanguinity and Children with Disabilities



Whilst the Children with Disabilities Team do not record whether parents are related reviewing the 10 deaths were consanguinity was a contributing factor and that all of these children were of Pakistani heritage it would seem that there is a link between consanguinity and children with disabilities.

Combining the 3 local authorities BME children with disabilities figures indicates that children of Pakistani heritage are largely represented. As consanguinity is not recorded in information held by the Children with Disabilities Team it’s difficult to identify which families are consanguineous and how this may have contributed to the child’s disability. The statistics can be used to provide a better understanding and explanation of why children from the BME community are overrepresented. A common theme across the three local authorities is that children with disabilities of Pakistani heritage are the most prevalent ethnic group within the BME community. The figures suggest that there is a link between consanguinity and children with disabilities given those consanguineous relationships and cousin marriage is most practiced within the Pakistani community.

## 16. Levels of Deprivation

<sup>12</sup>The Department for Communities and Local Government produced a 2010 release update of the English indices of deprivation 2007. The English indices of deprivation measure relative levels of deprivation in small areas of England called 'lower layer super output areas'. The indices of deprivation are currently being updated for publication in summer 2015.

The Index of Multiple Deprivation 2010 contains seven domains of deprivation:

- Income deprivation
- Employment deprivation
- Health deprivation and disability
- Education, skills and training deprivation
- Barriers to housing and services
- Living environment deprivation
- Crime

The level of deprivation is measured taking into account the above 7 areas and indicates where each borough sits of the total 326 local authorities.

Most Deprived	Rochdale	29/326
	Oldham	46/326
Least Deprived	Bury	119/326

### Bury

<sup>13</sup>The health of people in Bury is varied compared with the England average. Deprivation is lower than average, however about 6,800 children live in poverty.

Life expectancy for both men and women is lower than the England average. Life expectancy is 10.8 years lower for men and 8.0 years lower for women in the most deprived areas of Bury than in the least deprived areas. Over the last 10 years, all cause mortality rates have fallen. The early death rate from heart disease and stroke has fallen and is worse than the England average.

In Year 6, 18.9% of children are classified as obese. Levels of alcohol-specific hospital stays among those worse than the England average. The level of GCSE under 18, breast feeding and smoking in pregnancy are attainment is better than the England average.

The estimated level of adult obesity is better than the England average. Rates of smoking related deaths and hospital stays for alcohol related harm are worse than the England average. Rates of sexually transmitted infections and road injuries and deaths are better than the England average.

### Rochdale

The health of people in Rochdale is generally worse than the England average. Deprivation is higher than average and about 12,000 children live in poverty.

Life expectancy for both men and women is lower than the England average. Life expectancy is 11.6 years lower for men and 9.9 years lower for women in the most deprived areas of Rochdale than in the least deprived areas. Over the last 10 years, all cause mortality rates have fallen. The early death rate from heart disease and stroke has fallen and is worse than the England average.

<sup>12</sup> English indices of deprivation 2010 <https://www.gov.uk/government/statistics/english-indices-of-deprivation-2010>

<sup>13</sup> 2013 Public Health Profiles [http://www.apho.org.uk/default.aspx?QN=P\\_HEALTH\\_PROFILES](http://www.apho.org.uk/default.aspx?QN=P_HEALTH_PROFILES)

In Year 6, 21.5% of children are classified as obese, worse than the average for England. Levels of teenage stays among those under 18, breast feeding and pregnancy, GCSE attainment, alcohol-specific hospital smoking in pregnancy are worse than the England average.

Estimated levels of adult 'healthy eating' and smoking are worse than the England average. Rates of smoking related deaths and hospital stays for alcohol related harm are worse than the England average. Rates of sexually transmitted infections and road injuries and deaths are better than the England average.

## Oldham

The health of people in Oldham is generally worse than the England average. Deprivation is higher than average and about 13,500 children live in poverty.

Life expectancy for both men and women is lower than the England average. Life expectancy is 11.1 years lower for men and 10.3 years lower for women in the most deprived areas of Oldham than in the least deprived areas. Over the last 10 years, all cause mortality rates have fallen. Early death rates from cancer and from heart disease and stroke have fallen but remain worse than the England average.

In Year 6, 20.2% of children are classified as obese. Levels of teenage pregnancy, GCSE attainment, breast feeding and smoking in pregnancy are worse alcohol-specific hospital stays among those under 18, than the England average.

Estimated levels of adult 'healthy eating', smoking, physical activity and obesity are worse than the England average. Rates of smoking related deaths and hospital stays for alcohol related harm are worse than the England average. Rates of sexually transmitted infections and road injuries and deaths are better than the England average. The rates of statutory homelessness and incidence of malignant melanoma are better than average.

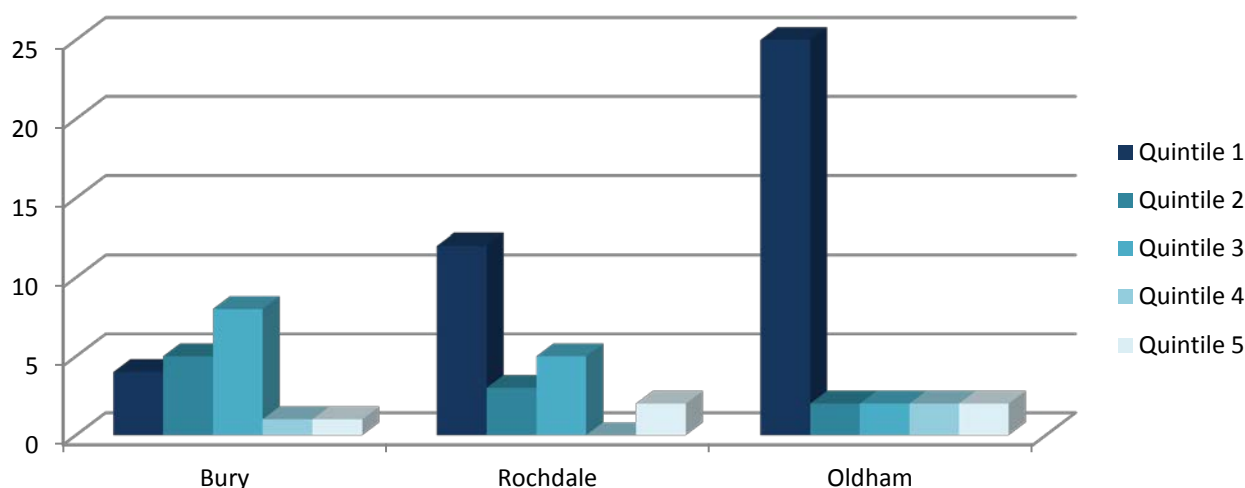
## Quintiles

Each area within the local authorities is split into one of the five quintiles to determine the level of deprivation ranging from Quintile 1 as most deprived and Quintile 5 as the least deprived. Quintiles are based on statistical value of a data set that represents 20% of a given population.

The first quartile represents the lowest fifth of the data (1-20%); the second quartile represents the second fifth (21% - 40%) etc. The quintiles are broken down into:

- Quintile 1: Most deprived
- Quintile 2: 2nd Most Deprived
- Quintile 3: Mid Deprived
- Quintile 4: 2nd Least deprived
- Quintile 5: Least deprived

The below data is based on the 74 child death notifications received between 1 April 2013 and 31 March 2014.



	Bury		Rochdale		Oldham		Total	
Quintile 1 (Most Deprived)	4	21%	12	55%	25	76%	41	55%
Quintile 2	5	26%	3	14%	<3	6%	10	14%
Quintile 3 (Mid Deprived)	8	42%	5	23%	<3	6%	15	20%
Quintile 4	<3	5%	0	0%	<3	6%	3	4%
Quintile 5 (Least Deprived)	<3	5%	<3	9%	<3	6%	5	7%
Total	19	100%	22	100%	33	100%	74	100%

Of the 74 child death notifications received the largest number of deaths occurred where the child/family resided in areas of deprivation (quintile 1 and 2) totalling 69% (51) of the total deaths. Of these 51 child deaths in quintiles 1 and 2 a large percentage of deaths occurred in:

- 18 / 35% Neonates
- 11 / 22% Death of a life limiting condition
- 8 / 17% Sudden and Unexpected Death in Infancy

## Bury

Unlike Oldham and Rochdale, Bury received the largest number of child deaths in quintile 3 (mid deprived) with 8 (42%) of the 19 deaths. Of the 8 deaths in quintile 3, there was a 50/50 split between male and female deaths. 62% (5) of the children were of White English/Welsh/Scottish/N Irish/British ethnicity and the remaining 38% (3) were from the BME community. Of the 8 deaths in quintile 3 neonatal deaths were the most represented with 63% (5).

Of the total 19 Bury child deaths reported to CDOP in 2013/14 the largest number of deaths occurred in the ward Sedgley (7 / 37%).

## Rochdale

In Rochdale the largest number of deaths occurred in quintile 1 with 12 (55%) of the 22 deaths. Of the 12 deaths in quintile 1, 50% (6) of children were of White English/Welsh/Scottish/N Irish/British ethnicity and 42% (5) from the Asian Pakistani community. Data shows that there was a much higher percentage of male deaths (11 / 92%) to female (1 / 8%) Of the 12 deaths in quintile 1 neonatal deaths (4 / 33%) and deaths due to a life limiting condition (4 / 33%) were the most represented.

Of the 22 Rochdale child deaths reported to CDOP in 2013/14 the largest number of death occurred in the wards Healy (3 / 14%) and Kingsway (3 / 14%).

## Oldham

In Oldham the largest number of deaths occurred in quintile 1 with 25 (76%) of the 33 deaths. Of the 25 deaths in quintile 1, the largest number of deaths with 48% (12) were children of Pakistani heritage, 24% (6) White/White British and 20% (5) Bangladeshi. Overall the BME community was largely represented in child deaths within quintile 1 with 76% (19) of deaths. Of the 25 deaths 56% (14) were male and 44% (11) female.

Of the total 33 Oldham child deaths reported to CDOP in 2013/14 the largest number of deaths occurred in the ward Werneth (8 / 24%).



## 17. Sudden Unexpected Death in Infancy (SUDI)

Sudden Unexpected Deaths in Infancy (SUDI) is the medical term used to describe the sudden and unexpected death of a baby or toddler that is initially unexplained. Some sudden and unexpected infant deaths can be explained by the post-mortem examination revealing, for example, an unforeseen infection or metabolic disorder. Deaths that remain unexplained after the post mortem and the cause of death cannot be established are categorised as SUDIs.

The CDOP initially classifies the case as a SUDI pending the outcome of the Coroner's investigation. If the cause of death is established from the post mortem and it's identified that the child died, for example, due to infection, the case would no longer meet SUDI criteria. Where it remains that the cause of death is unascertained, these cases are categorised as SUDI.

From the 1 April 2013 to 31 March 2014 the CDOP was notified of 7 potential SUDI child deaths. Following the conclusion of a post mortem examination and/or inquest the Pathologist and the Coroner has ascertained the cause of death as Unascertained/Natural Causes (of unascertained origin) for 5 of the SUDI deaths.

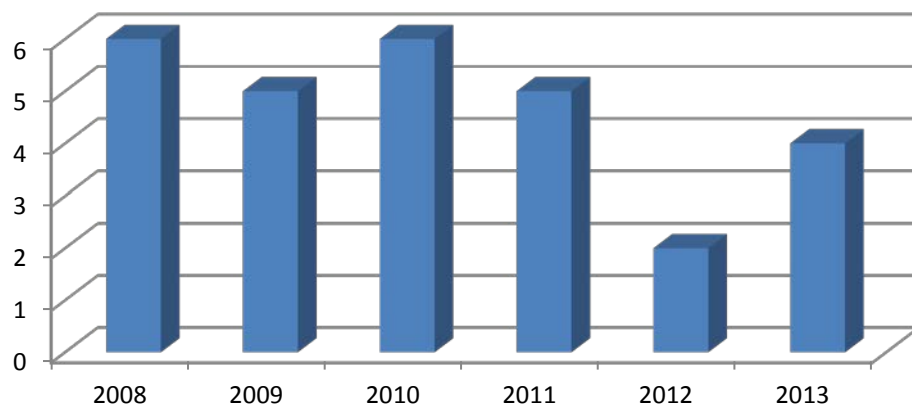
Of the 5 confirmed SUDI deaths co-sleeping on a sofa or in a parental bed was identified in 3 of the cases where overheating was documented as a risk factor. As numbers are small a breakdown of SUDI deaths year on year provides a more detailed overview of the emerging trends.

### Sudden Unexpected Death in Infancy (SUDI) Year on Year

Of the child deaths referred to the CDOP between April 2008 and March 2014 the panel categorised and closed 28 cases as SUDI. There is currently an additional 4 potential SUDI cases that are awaiting a cause of death from the Coroner's Office to confirm whether the death was a SUDI or due to an underlying medical condition or infection. The 28 cases are made up of:

Bury	9	32%
Oldham	9	32%
Rochdale	10	36%
Total	28	

Reviewing the cases by the child's year of death provides an overview of the increase/decrease in the number of SUDI deaths year on year.



2008	6
2009	5
2010	6
2011	5
2012	<3
2013	4
Total	28

Reviewing the cases highlighted:

- 12 (43%) of the deaths were female and the remaining 16 (57%) were male
- Of the 28 SUDI deaths ethnicity was recorded in 27 of the cases. 20 (74%) deaths were of the ethnicity White/White British and 7 (26%) from the BME community
- 6 (21%) deaths occurred aged 0 – 28 days of life, 21 (75%) deaths occurred aged 29 – 364 days and 1 (4%) death aged 1 – 4 years
- 11 (39%) of the children were resident in quintile 1 (most deprived area), 5 (18%) in quintile 2 (second most deprived area), 7 (25%) in quintile 3 and 4 (14%) in quintile 4. The largest number of deaths occurred where the child was resident in a deprived area with 57% (16) of the deaths.
- Mothers smoking status was recorded in 23 of the 28 cases. It was recorded that Mother smoked in 13 (57%) of the cases and 10 (43%) Mothers stated that they did not smoke.
- Co-sleeping had taken place with parents and/or siblings in bed or on a sofa in 17 (61%) of the deaths.
- It was noted in 9 (32%) of the cases that alcohol was consumed by parents on the evening/morning of death and that co-sleeping was also a factor in these 9 cases.
- The child's gestation was recorded in 27 of the 28 SUDI deaths. Of the 27 deaths where gestation was recorded 8 (30%) of the babies were born premature (<37 weeks gestation).
- Birth weight was recorded in 25 of the 28 SUDI deaths. Of these 25 cases the child's birth weight was recorded as low for 6 (25%) of the children.

Of the 28 SUDI cases the CDOP categorised 19 (68%) deaths as having modifiable factors. This is where the panel have identified one or more factors, in any domain, which may have contributed to the death of the child and which, by means of locally or nationally achievable interventions, could be modified to reduce the risk of future child deaths. Of the 19 cases where modifiable factors were identified one or more of the following risk factors were highlighted:

- Co-sleeping (with parents and/or other siblings in bed or on a sofa)
- Ingestion of illegal substances such as cannabis
- Prescribed medication such as anti-depressants
- Smoking during pregnancy
- Parental smoking within the family home
- Overheating/over wrapping
- Alcohol consumption on the evening or morning of the event
- Overcrowding housing arrangements
- Poor home conditions an environment
- Chaotic lifestyles
- Lack of uptake to antenatal care/concealed pregnancy
- Lack of engagement with services such health services as GP and Health Visitors
- Late immunisations

Year on year the CDOPs across the UK review the number of SUDI cases and the contributing risk factors identified. In previous years the CDOP annual report has requested information regarding resources provided to parents a various stages of pregnancy and birth such as:

- Antenatally
- Birth (on the ward)
- Discharge and
- Home Visits

The Pennine Acute Hospital developed the information guide 'Putting your baby down to sleep safely' which advises that parents:

*Never sleep with your baby if either you or your partner*

- *has taken any legal or illegal drugs*
- *has been drinking alcohol*
- *is a smoker*  
*or if*
- *your baby was born small or premature*

*Do not put yourself, or allow others to be, in a position where there is a possibility of dozing off with the baby on a sofa or armchair, as this is one of the highest risk factors for sudden infant death.*

The Pennine Acute Hospital policy states that the leaflet should be provided to every new Mother and discussed on the labour ward. Information is provided on the postnatal ward where notes are stamped, dated and signed to record the discussion held. The message is also reinforced at discharge and at the first home visit from the community midwife. An internal audit in Pennine Acute identified some gaps and that the service was not always fully compliant. Further work is required to ensure that all Mothers receive the correct information regarding safe sleeping arrangements to improve consistency and the Pennine Acute are in the process of updating action plans to achieve this.

Information regarding SUDI is also contained in the Personal Child Health Record (PCHR) also known as "the red book". The booklet contains information for parents highlighting safe sleeping arrangement do's and don'ts stating that '*The safest place for your baby to sleep is on their back in a cot or a crib in the room with you for the first six months*'. The Safe Sleeping Assessment and Action Plan are completed by the midwife and contain questions regarding breastfeeding, safe sleeping, smoking and alcohol consumption. Any identified risk factors are highlighted and actions produced with timescales to address any concerns.

## Safe Sleeping Information

[The Lullaby Trust](#) provides useful information such as videos, leaflets and quick tips for safer sleep:

### Things to do

- Always place your baby on their back to sleep
- Keep your baby smoke free during pregnancy and after birth
- Place your baby to sleep in a separate cot or Moses basket in the same room as you for the first 6 months
- Breastfeed your baby, if you can
- Use a firm, flat, waterproof mattress in good condition

### Things to avoid

- Never sleep on a sofa or in an armchair with your baby
- Don't sleep in the same bed as your baby if you smoke, drink or take drugs or are extremely tired, if your baby was born prematurely or was of low birth-weight
- Avoid letting your baby get too hot
- Don't cover your baby's face or head while sleeping or use loose bedding

The Lullaby Trust has developed the [Safe Sleep for Babies: A Guide for Parents](#) leaflet which provides a more detailed overview of how parents can reduce the risk of SUDI.

Parents who have suffered a sudden and unexpected death of a baby often feel anxious in future pregnancies. The Lullaby Trust has been working with the NHS to run a national health-visitor led service for bereaved parents, [Care of Next Infant \(CONI\)](#) programme, which supports families before and after the birth of their new baby. CONI is run in hospitals and community health centres and involves health visitors, midwives, paediatricians and GPs.

Through CONI, parents can:

- receive regular home visits by their health visitor, so they can talk freely about any worries and seek advice
- keep a symptom diary to record their baby's health, which they can then discuss with their health visitor
- use the Baby Check booklet to help decide when their baby should be examined by a doctor
- monitor their baby's growth with a weight chart and weighing scales, to detect changes quickly
- borrow apnoea (breathing) monitors which pick up movements as the baby breathes, and will ring an alarm if movements stop for longer than 20 seconds
- receive training on resuscitation
- receive a room thermometer and guidance on bedding and clothing

The CONI scheme is offered to parents across Bury, Rochdale and Oldham who present in pregnancy following a previous SUDI child death or neonatal death. The referral to CONI is usually completed by the Midwife or Health Visitor during the antenatal assessment once Mother reaches 28 weeks gestation. The scheme offers a more intense level of service to provide parents with additional support and reassurance during pregnancy. The core elements of the programme include regular contacts with a health visitor, symptom diaries, weight charts and apnoea (movement) monitors.

## 18. Suicides

From April 2008 to March 2014 there have been 7 child deaths reported to CDOP due to suicide.

- The children were aged between 13 – 17 years of age
- 3 of the deaths occurred in 2012
- 5 of the children died as a result of hanging at the parental home
- The largest number of deaths occurred in Bury (3) and Rochdale (3)
- 5 children were male
- Ethnicity was recorded in 6 of the cases, 5 of which were recorded as White/British
- 3 children were resident in quintiles 1 and 2 (most deprived) and 3 children resident in quintiles 4 and 5 (least deprived).

The CDOP continues to monitor the number of suicides and works with neighbouring Greater Manchester CDOPs to investigate emerging themes. The Greater Manchester Safeguarding Partnership has requested statistics from the 4 CDOPs in relation to child deaths following apparent suicide. This will provide the CDOPs with a much larger footprint to review and highlight any trends to potentially undertake collaborative working to reduce the number of suicides.

# 19. Ingestion of Hazardous Substances

There have been a small number of child deaths following the ingestion of a battery and a further 5 children who have suffered 'life-changing' injuries in Greater Manchester in the last 18 months. The lithium batteries are common in many homes, and are found in many items including smartphones, key cards, children's games, watches, toys and even children's books.

If swallowed, the batteries can cause severe internal bleeding which is very difficult to treat. Following the ingestion of a battery the child may seem fine at first and may not show any signs of choking or poisoning. In some cases, they may develop cold or flu-like symptoms developing a fever and/or vomiting. Button batteries are also dangerous if children put them into their noses and ears.

The [Child Accident and Prevention Trust](#) (CAPT) have drawn attention to the danger posed by button batteries and are urging practitioners to get the warning out to as many parents and carers as possible. CAPT have also developed leaflets and posters highlighting the dangers of button batteries and are available via the CAPT website. The media has also raised awareness of the dangers of button batteries regionally and nationally via [BBC News](#) and documented on TV programmes The One Show.

At a recent Inquest Hearing following the death of a child who ingested a button battery, the Coroner Simon Nelson is in the process of writing to the Department of Health to raise awareness of the harm batteries can cause to children if swallowed stating *"I believe that preventions and precautions need to be extended to include child-resistant packaging for batteries."*

Although the CDOP has received a very small number of child deaths due the ingestion of hazardous substances the panel has identified this as a risk within the home and has undertaken awareness raising to help prevent future deaths. In October 2014 the CDOP distributed [The Royal Society for Prevention of Accidents](#) (RoSPA) poster to children centres across Bury, Rochdale and Oldham and asked that they be displayed within the centres to raise awareness amongst staff and parents. . The RoSPA post highlights the dangers of nappy sacks, batteries, liquitabs and blind cords.



Distributors of liquid tabs such as Ariel have also been proactive in promoting the safety message 'Keep liquid tabs out of children's reach and sight' which is also publicised through social media websites.



In November 2014 the Oldham Local Authority Designated Officer (LADO) held a 2 safeguarding training events for nearly 80 child minders and nursery workers in Oldham. The CDOP Officer attended and provided information and relevant statistics regarding the most vulnerable age group which is child deaths under the age of one. Some of the specific dangers highlighted included:

- Nappy sacks
- Cord blinds
- Liquid tabs
- Batteries
- Pro-longed sleeping in car seats
- Co-Sleeping/Safe Sleeping and

Staff were provided with a link to the RoSPA poster and asked to display the poster in their nursery to help raise awareness.

## 20. Recommendations

The 2012/2013 CDOP Annual Report produced 3 recommendations highlighting the following:

### 1. Investigating the disproportionate number of BME deaths

The 2011/12 CDOP Annual Report highlighted the disproportionate number of child deaths within the BME community in comparison to the BME child population. This is a continuing trend and is also highlighted in the 2012/13 data set.

Of the Greater Manchester child population, the BME community is made up of 25% in comparison Oldham and Rochdale have a higher percentage of children in this community. Whilst Rochdale's BME child population is made up of 29%, 40.7% of the deaths were accounted for. In Oldham there were more deaths from the BME community than those of White/British. Oldham's BME child population is made up of 36.5% in comparison to the 54.5% of deaths.

Of the total 65 child deaths 26 (41.2%) of these were from the BME community. Of the 26 BME deaths, consanguinity was relevant and directly linked to 23.1% (6) of the child deaths.

When reviewing the number of child deaths who resided in areas of deprivation it would appear that a large percentage of these children were from the BME community. Of the 49 deaths in areas of deprivation (quintile 1 and 2), 53.1% (26) of these were made up of children from BME communities.

Oldham and Rochdale should conduct further analysis to review the overrepresented BME deaths and link information regarding areas of deprivation to identify any emerging themes.

### 2013/14 Update

Year on year the CDOP has highlighted an ongoing trend when comparing the number of BME child deaths to the BME child population. The CDOP continues to monitor and investigate the overrepresentation of child deaths within the BME community. This year the report suggested a link between BME child deaths, BME children with disabilities, consanguineous relationships and families that live in areas of deprivation.

Of the 37 BME child deaths referred to CDOP in 2013/14 it was identified that 10 (27%) of these deaths were directly linked to consanguinity, all of which are of Pakistani heritage thus accounting for a large proportion of the BME child deaths. Reviewing the ethnicity of the total 74 child deaths notifications in 2013/14 indicates that consanguinity accounted for 14% (10) of the overall deaths.

There is a clear link between consanguinity and the disproportionate number of children with disabilities and child deaths from the BME community. The Oldham Consanguinity Task Group has reviewed the existing processes in place to support the BME community via Saint Mary's Genetic Counselling and the support offered to families who are deemed most at risk. Oldham wishes to extend the services and information provided to the community and suggested a two strand approach

1. Reactive approach - To continue working with families that are at risk and increase the capacity by employing a specialist geneticist to undertake work in the community
2. Proactive approach – To raise awareness within educational settings to highlight the associated health risks of consanguineous relationships/marriages to ensure that the community has received appropriate information to make an informed decision.

See Recommendation 3 'Raising awareness of consanguinity and the associated health risks' for further information

## 2. Co-ordinating a consistent safe Sleeping message

There have been numerous public campaigns in neighbouring local authorities and national awareness raising of the potential risks of co-sleeping. Whilst it appears that the number of SUDI deaths has reduced there needs to be a clear and consistent message provided to parents.

Health settings across Greater Manchester need to ensure consistency, to agree on a leaflet and that the same information is provided to all parents, prior to discharge, to reinforce the message that 'The safest place for your baby to sleep is on their back in a cot or a crib in the room with you for the first six months'.

In the 21 SUDI cases where Mothers smoking status was recorded, 57.1% (12) of Mothers stated that they smoked. There needs to be an agreed consistent message to advise parents that they should **never** sleep with their baby if they or their partner:

- has taken any legal or illegal drugs
- has been drinking alcohol
- is a smoker

Parental discussions prior to discharge regarding the risks of smoking and co-sleeping should be recorded within the patient's medical notes. It would be useful to undertake regular audits to ensure the message is disseminated appropriately to all parents.

### 2013/14 Update

As part of the UNICEF audit the Pennine Acute regularly audit bed sharing information provided to Mothers in writing, the discussions held and risk assessments completed (Child Health Records).

The Pennine Acute Hospital continues to provide the information guide 'Putting your baby down to sleep safely' which advises that parents:

*Never sleep with your baby if either you or your partner*

- *has taken any legal or illegal drugs*
- *has been drinking alcohol*
- *is a smoker*  
*or if*
- *your baby was born small or premature*

*Do not put yourself, or allow others to be, in a position where there is a possibility of dozing off with the baby on a sofa or armchair, as this is one of the highest risk factors for sudden infant death.*

The Pennine Acute Hospital policy states that the leaflet should be provided to every new Mother and discussed on the labour ward. Information is provided on the postnatal ward where notes are stamped, dated and signed to record the discussion held. The message is also reinforced at discharge and at the first home visit from the community midwife. An internal audit in Pennine Acute identified some gaps and that the service was not always fully compliant. Further work is required to ensure that all Mothers receive the correct information regarding safe sleeping arrangements to improve consistency. The Pennine Acute are in the process of updating action plans to achieve this.

The November 2014 audit showed that 77% of Pennine Acute Mothers received this information and the risk assessment was completed on the postnatal ward in the early 12 hours post birth. The community audit increased this figure to 88% of Mothers having this advice (links to early discharge). The Pennine Acute appreciate that further work is required to ensure that all Mothers receive the correct information regarding safe sleeping arrangements to improve consistency and are in the process of updating action plans to achieve this.

Information regarding safe sleeping and reducing the chances of infant death continues to be provided in the Personal Child Health Record (PCHR) also known as "the red book". The booklet contains information for parents highlighting safe sleeping arrangement do's and don'ts stating that '*The safest place for your baby to sleep is on their back in a cot or a crib in the room with you for the first six months*'.

The Safe Sleeping Assessment and Action Plan are completed by the midwife and contain questions regarding breastfeeding, safe sleeping, smoking and alcohol consumption. Any identified risk factors are highlighted and actions produced with timescales to address any concerns.



### 3. Raising awareness of consanguinity and the associated health risks

From the statistical information collated it's clear that the largest number of consanguineous deaths occurred in children of Pakistani heritage. These deaths are most prevalent in Oldham and Rochdale as both local authorities population have a larger percentage of the BME community in comparison to Bury. Whilst Oldham continues to raise awareness with professionals there have been struggles on how to effectively communicate the message to the general public. Public Health is to present the consanguinity report to the Health and Wellbeing Board to suggest ways forward on how to deliver the message within the community. It would be useful for Rochdale to adopt a similar process to maintain a good level of consistency across the boroughs and that parents entering cousin relationships/marriage are aware of the potential health risks. Oldham and Rochdale Public Health are required to lead the project and agree effective methods of communication to raise awareness within the community.

As the first point of contact for families, it is important that GPs reiterate the associated health risks linked to consanguinity to enable parents to make informed decisions. Where it is identified that families are at an increased risk of inherited genetic abnormalities, these cases should be referred onto St Marys to provide genetic counselling.

Whilst there is sufficient data to establish the links between child deaths and consanguinity there remains gaps in information regarding the disproportionate number of children with disabilities from the BME community. Developing the Social Care system to record parent's relationship would provide a better knowledge on the impact consanguinity has on the health service and the disabilities linked to inherited genital abnormalities.

#### 2013/14 Update

As detailed in Section 15: Consanguinity of the annual report, year on year the CDOP is becoming more robust at collating data in relation to consanguinity. Section 15: Consanguinity of the report provides an overview of how consanguinity affects the population and raises questions regarding the cost implications this has for the NHS and Social Care. Calculating the cost implications and impact on the health service is difficult to estimate as every condition is varied and requires various sources of treatment and care depending on the child's diagnosis, the severity of their condition and the life expectancy of the child.

The Oldham Consanguinity Task Group reviewed local authority's campaigns such as Birmingham and Bradford who have also identified consanguinity as a risk factor regarding the associated health risks. Oldham reviewed the pros and cons of these campaigns to look at lessons learnt and establish what information is currently provided to the community and the best way forward.

At present the GP/hospital may refer a family to Saint Mary's Genetic Counselling Service where a genetics counsellor works one day a week in Oldham. However they do not have the capacity to undertake any preventative work or general awareness raising within the community.

Oldham LSCBs drafted the consanguinity report which was presented to the Health and Wellbeing Board to look at the next steps forward to increase capacity and continue working with families who are most at risk and to raise awareness within the community by providing information in college settings regarding the associated health risks.

Oldham LSCB wishes to implement the following proposal:

1. Targeted work to raise awareness within the communities at risk with the aim that people understand that, if there is a family history which raises concerns, they should seek specialist advice. The aim is to ensure that members of the public understand the associated health risks linked to consanguineous relationships to make informed decisions before considering marriage
2. Raising awareness amongst front-line health professionals about the issue enabling them to contribute to the awareness raising, provide the appropriate information and initiate referrals where needed
3. Increasing the capacity of the Saint Mary's service to provide genetic counselling, and to undertake community outreach work.

At present the report is to be presented to the Clinical Commissioning Group (CCG) to discuss resources to fund and employ a specialist genetics post who can carry out the proposal.

## 21. 2013/2013 Action Plan

Reviewing recommendations from previous years highlights the same emerging themes for 2013/2014 in relation to:

- the disproportionate number of deaths within the BME community
- co-ordinating a consistent safe sleeping message and
- consanguinity and the associated health risks

This year the Annual Report identified a link between consanguineous relationships and the disproportionate number of children with disabilities and child deaths within the BME community. Many of the issues raised within the report will remain ongoing pieces of work which specific agencies such as Health and the CDOP will continue to monitor.

The CDOP produced the 2013/14 Action Plan which provides an update of work ongoing from 2012/2013. Many of these items will be carried forward to 2013/2014 and submitted to the 3 Local Safeguarding Children Boards.