LUTON BOROUGH COUNCIL

SCRUTINY TASK & FINISH GROUP

INFANT MORTALITY

Final Report

November 2013

CONTENTS

Members of the Review Group

Members	Membership (chair appointed at first meeting)
Councillor Cato	**Member**
Councillor Foord	**Member**
Councillor Knight	**Member (Joined on 12/05/13)**
Councillor T. Malik	**Member (Joined on 12/05/13)**
Councillor Rivers	**Member**
Councillor Whittaker	**Chair**
Ms. Andrea Assan	**(Healthwatch – Luton) co-optee**

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List of Advisers/ Witnesses

OFFICERS	TITLES	ORGANISATIONS
Dr Monica Alabi	Children's Champion Luton's Clinical Commissioning Group	Luton Clinical Commissioning Group
Dr. Beryl Alder	Clinical Director for Paediatricians	National Health Service
Paula Doherty	Children's Integrated Commissioning Team	Luton Clinical Commissioning Group
Eunice Lewis-Okeowo	(Project Co-ordinator)	Luton Borough Council
Christopher Hall	Press & Public Relations Manager	Luton Borough Council
Farah Ishmail	Consultation Officer	Luton Borough Council
Lisa Levy	Communications Officer	Luton Borough Council
Helen Lucas	Head of Midwifery-L&D	Luton &Dunstable Hospital
Dr. Catherine Kearney Redgrave Children and Young People Centre,	Consultant Community Paediatrician - lead for CDOP, Luton	National Health Service
Gerry Taylor	Director of Public Health	Luton Borough Council
Kelly O'Neill	Assistant Director of Public Health & Lead on IM	Luton Borough Council
Sue Steffens	Assistant Director/Designated Nurse Safeguarding Children LCCG	National Health Service, Luton Clinical Commissioning Group (Child Death Overview Process)
Caroline Thickens	Public Health Information Analyst	National Health Service /Luton Borough Council
Shirley Whiterod	Manager Bedfordshire & Luton (CDOP) (Child Death Overview Process)	National Health Service Bedfordshire

CHAIR'S FOREWORD

The death of a child is a tragedy for the family and the wider community. In Luton, the significantly higher than national Infant Mortality Rate (IMR) has been a cause for concern for some years. It is vital that we do all we can to tackle infant mortality, and because of this the Overview and Scrutiny Board commissioned this task and finish review group, which it has been my privilege to chair.

The group recognise and commend the progress already being made on this topic by a wide range of stakeholders. The group felt that it was important for the review to add value to the existing work. The key was to help understand why the Infant Mortality Rate was so high in Luton, and to identify what more could be done to reduce it.

Throughout the review, the Group worked very closely with officers from the Council and stakeholders from across the National Health Service and the University of Bedfordshire. Everyone involved brought their own unique perspective and insight to the Group. The University of Bedfordshire was able to broaden the perspective of the review beyond Luton. It was encouraging to see that there was already a partnership and a work programme between research staff from the University and Public Health. Indeed, the whole review was an excellent example of partnership working.

Infant Mortality is a complex and sensitive subject to review, made possible by the hard work of all involved. I would like to place on record my appreciation and thanks to all the members and officers for their invaluable contributions and in particular the Task and Finish Group Coordinator.

As Chair of the review, it is my privilege and pleasure to commend this report and recommendations to all the relevant agencies concerned.

I hope the recommendations will help improve outcomes and have a positive impact on families and babies in Luton.

Councillor Roxanna Whittaker

CHAIR

EXECUTIVE SUMMARY

(i) The Task and Finish Group set out to address and to investigate a number of key factors and causes of infant mortality in Luton including links to deprivation, poverty, maternal obesity, smoking in pregnancy lifestyle, consanguinity and genetic issues.

(ii) The Task and Finish Group mapped out 4 expected outcomes to keep the debate on track and to ensure that the key indicators were identified and thoroughly explored in order for the review to achieve its purpose. The 4 expected outcomes are highlighted in section 4 of this report.

(iii) The Task and Finish Group acknowledges that Luton Borough Council's Public Health together with Luton Clinical Commissioning Group (CCG), NHS Partners from Luton and Dunstable Hospital and the University of Bedfordshire were already working together on infant mortality as part of their priority for a Healthier Luton.

(iv) Over the last couple of years, infant mortality in Luton had dropped in line with the rest of the Country but the Infant Mortality Rates (IMR) remain above average at 7.5 per 1,000 live births between 2008-10 compared to 4.5 deaths in England and Wales for the same period. **(Source: Improving Health and Wellbeing 2012-217 (Health and Wellbeing Strategy) page 25).** Recent data (2010-12) shows that the gap between Luton and England is closing with Luton IMR down to 5.3 deaths per 1,000 live births from 7.2 in 2009-11. **(Source: Infant Mortality Plan Paper submitted at the T&FG meeting on 12th September 2013).** The more current data is due to be published in December 2013. However the Luton infant mortality rate remains above the national average and it is vital that Luton takes appropriate action to continue to reduce rate of infant mortality.

(v) The Task and Finish Group will demonstrate that services are already aware of the key issues. The Council's Public Health have developed an Infant Mortality Action Plan, to continue to take the work forward using the information from the Child Death Overview Process Panel (CDOP) set up in 2008 with statutory responsibility to review the death of every child under 18 years of age in Luton and Bedfordshire.

(vi) Through the recommendations, the Task and Finish Group hopes that all services will continue to work together to help reduce infant mortality in Luton.

(vii) The Task and Finish Group agreed the following exclusions during its investigation:

- Process of investigating child abuse and sudden unexpected death in infancy (SUDI)
- Child bereavement process

RECOMMENDATIONS

Recommendation 1 – (Paragraph 8.8)
That the Executive commends the efforts of officers in Public Health, Social Justice and Partners in investigating key issues around welfare reform, but are recommended to work jointly with partners to identify the impact of the welfare reform on infant mortality to ensure appropriate steps are taken to minimise its impact on the Luton population.

Action Required:
All services to note and continue with current initiatives of work stream integration to identify the impact of welfare reform and target specific groups most impacted by risk of infant mortality in the deprived wards.

Recommendation 2 - (Paragraph 8.9)

That the Executive instructs the Director of Public Health to review the Family Poverty Strategy to establish links between the effects of poverty on infant mortality.

Action Required:
That a report of any links between the Family Poverty Strategy, and Infant Mortality, be reported to the Health and Social Care Review Group for comments.

Recommendation 3 – (Paragraph 9.2)

The Task and Finish Group acknowledges that data collation on the Infant mortality Rate (IMR) has improved in the last few years, since CDOP was set up in 2008. However, the Executive request the Director of Public Health to continue to take all necessary steps to improve data collection and analysis and ensure relevant information on IMR is easier to assess. The IM data from the deaths database should be used in conjunction with the CDOP data as this generates a more detailed picture of the death and associated risk.

Action Required

That the Director of Public Health be instructed to continue to take the necessary steps to improve IMR data collection and analysis to ensure results of the analysis are easier to assess.

Recommendation 4 – (Paragraph 9.4)
That the Executive requests the Director of Public Health to submit a report on the findings of the audit of gender imbalance of 2011/12 infant mortality to the Health and Social Care Review Group.

Action Required:
Report on the audit of gender imbalance findings to be submitted to the Health and Social Care Review Group by the Director of Public Health.

Recommendation 5 – (Paragraph 9.8)
That the Luton Clinical Commissioning Group (LCCG) be requested to ensure genetic screening is made more accessible and Public Health to raise awareness amongst health professional and the public to increase uptake with a focus on education and general engagement on the issue through religious leaders in the community.

Action Required:

(i) The LCCG should Commission
(ii) Public Health to promote

That Public Health encourages schools and health partners to work together with communities and faith groups to encourage greater awareness of and uptake of genetic screening.

Recommendation 6 – (Paragraph 9.11)
The Task and Finish Group commends and recognises the research work on genetics already being commissioned with the University of Bedfordshire and recommends that the research findings are used to influence the Council's policies and other health agencies to engage the community on the issue of genetics in general but also with a clear focus on consanguinity.

Action Required:
That the Director of Public Health use the findings on genetics to inform best practice to be communicated to religious groups, schools, agencies, etc.

Recommendation 7 – (Paragraph 9.12)
That the Executive request the Director of Public Health to continue to improve community engagement to explore options and ways to address infant mortality and this be communicated in ways that best meet the needs of the local community.

Action Required:

(a) That the Director of Public Health encourages commissioners to ensure that local need to reduce infant mortality through training and service provision by maternity, general practice and early years health professionals including health visitors and children centre staff with skills to inform women at increased risk of infant mortality in a sensitive, supportive and helpful manner.

(b) That the Director of Public Health ensures increased joint working with stakeholders through the "Better Together" agenda to communicate this message further.

Recommendation 8 – (Paragraph 10.8)
That the Executive request the Director of Public Health and health partners to organise an awareness raising campaign to inform people how to manage the associated risk of infant mortality to ensure continued reduction in the high rates of infant mortality.

Action Required:

(a) That a public resource document be developed explaining risk factors and risk minimisation to be accessible to families to tie into the awareness campaign; provide advice and tools to educated people in family planning, recognise lifestyle behaviours that impact on child health and signpost families to health support including families who may have increase risk of children with disabilities related to genetic conditions.

(b) That the Director of Public Health and University of Bedfordshire use existing mechanisms such as community engagement programmes in order to engage with all Luton residents as well as hard to reach groups, ensuring community involvement at all levels.

(c) That the Director of Public Health and health partners continue to raise awareness to address intergenerational attitudes and beliefs towards consanguineous relationships to openly

discuss these sensitive issues

Recommendation 9 – (Paragraph 10.12)

That the Executive request the Director of Public Health to continue to refresh and update the Infant Mortality Action Plan to ensure dynamic implementation and the inclusion of emerging risks in particular, the inclusion of the Child Poverty Strategy element.

Action Required:

(a) That the Infant Mortality Action Plan reflect the longer term effort needed on wider causes of infant mortality including child poverty, reducing the gap in educational attainment and improving employment opportunities in Luton.

(b) That work take place with the CDOP to generate more information on wider determinants impact (as appropriate) on each infant death investigated.

Recommendation 10 – (Paragraph 10.16)
That the Luton Clinical Commissioning Group (LCCG) consider re-establishing a patient and staff User Group for Maternity Services to encourage feedback to help identify issues and to help early intervention and prevention of incidents for continued service improvements.

Action Required:
To re-establish a system to encourage and record patient and staff feedback, to help identify and address issues in a timely manner.

Recommendation 11 – (Paragraph 10.17)
That the Executive request the Director of Public Health to set up an awareness raising programme on infant mortality risk factors throughout the borough to encourage women and their families to consider personal lifestyle choices, including reducing smoking, alcohol and substance misuse and maintaining a healthy lifestyle.

Action Required:
That awareness raising programmes be strengthened to focus on women with health and social needs, including those whose health behaviours indicate particular vulnerability and women living in localities and in communities with higher infant mortality. Those groups as well as any other identified as part of the dynamic information collection should be prioritised for support, including close working between midwifery and family support systems.

Recommendation 12 – (Paragraph 10.19)
That the Executive request the Director of Public Health to work with health partners including LCCG and Luton Local Healthwatch to carry out a consultation or survey which would evaluate the effectiveness of messages being communicated to those who require specialist support and or vulnerable groups.

Action required:
To carry out a consultation or survey which fully evaluates the effectiveness of health messages communicated to all vulnerable groups.

Recommendation 13 – (Paragraph 11.6)
That the Executive requests the Director of Public Health to widen access to the genetic counselling service in order to target pre-conceptions and give people the support they need to make informed choices.

Action required:
The Director of Public Health produce a leaflet, similar to the 'Bradford Every Baby Matters' initiative aimed at early intervention, to send the key messages and to help engage and inform Luton residents of options which should be displayed in key contact points in Luton such as:

(iii) The LCCG should Commission
(iv) Public Health to promote

- Health Centres
- Schools
- GP Surgeries
- Registry Offices
- Council offices, etc.

Recommendation 14 – (Paragraph 11.7)
That at the conclusion of the research on genetics by the University of Bedfordshire, the Director of Public Health be requested to submit a report outlining the methodology, recruitment and sample selection process, overall results, outcomes and recommendations to the Health and Social Care Review Group for comments and input before the final report is published.

Action required:
The report should include questions asked during the investigation. Also the Council's Consultation Team should be involved to help with the study to ensure engagement from a cross section of the community.

Recommendation 15 – (Paragraph 12.1)
That the Executive request the Director of Public Health, and the Luton Clinical Commissioning Group (LCCG) to respond to the Health and Social Care Review Group on the recommendations of the Infant Mortality Task and Finish Review Group within 28 days of receipt and also provide a progress report on those recommendations that are accepted to a future meeting of the Health and Social Care Review Group to be determined and included in the Committee's annual work programme.

Action Required:
That the Director of Public Health be requested by the Executive to coordinate all partners responses to the report and recommendations to the Health and Social Care Review Group for initial response and annual reporting.

Recommendation 16 – (Paragraph 12.4)
That the Executive is recommended to consider and approve the recommendations of the Infant Mortality Task & Finish Review Group and request the Director of Public Health to lead on and co-ordinate the implementation by all relevant agencies and provide feedback to the Scrutiny Health & Social Care Review Group as required.

Action Required:
That the final report be submitted to the Executive, following approval by the Overview and Scrutiny Board.

1. BACKGROUND

1.1 The Infant Mortality Rate in Luton was proposed by the Scrutiny Health and Social Care Review Group for in depth review during 2012-13 following presentation on "A Healthier Future for Luton" by Public Health Luton and Luton Clinical Commissioning Group (LCCG). The presentation highlighted Luton's infant mortality rate for 2008-10 was the 7th highest nationally at 7.5 infant deaths per 1,000 live births, significantly higher than England and Wales average of 4.5.

1.2 The proposal was endorsed by the Overview and Scrutiny Board in August 2012 to run for a period of 6 months starting in January 2013. However, due to the complexity and contentious nature of the topic, the review group sought an extension to conclude the review in October 2013.

DEFINITION OF INFANT MORATLITY RATE (IMR)

1.3 The Infant Mortality Rate can be defined as the number of deaths under the age of one year per 1,000 live births.

1.4 The infant mortality rate for Luton in the pooled three year period 2007-09 was 7.4 infant deaths per 1,000 live births and this was significantly higher than England and Wales at 4.7. The different periods of pooled data (as will be demonstrated throughout the review) shows that Luton's rate had been consistently higher than the national rate for the last 10 years with a significant increase first identified in the published pooled data for the three year period (2007-09). This increase was as a result of a significantly higher number of deaths in 2009. **(Source: Joint Strategic Needs Assessment 2011 –JSNA page 42). (Also see Appendix 1 attached to report)**

2. PURPOSE

2.1 The infant mortality rate in Luton were a cause for concern and the review was keen to add value to the existing work of the Council's Public Health, which was already leading on the delivery of an action plan and working with other health partners to tackle the high rate of infant deaths in Luton.

Targeting infant mortality is a key recommendation noted in a number of strategic documents namely:

- Joint Strategic Needs Assessment 2011 (JSNA)
- Director of Public Health Annual Report - 2011
- Children and Young People's Plan - 2011

The purpose of the review as set out in the scope of work was;

- To identify and address the key issues that will enable the Council and NHS partners including providers of health services to address evidence based interventions that will help contribute to reducing the IMR in Luton.

- To identify and consider factors and causes of high infant mortality in Luton and possible link between infant mortality and genetic inheritance.

3. OBJECTIVES

3.1 The main objectives of the review were:

- To engage with local communities to address the issues around infant mortality and possible link to health inequalities, lifestyle, deprivation and poverty, etc.
- To recognise and identify factors and causes of infant mortality, some of which may be culturally sensitive (e.g.) preconceptions and misconceptions regarding marriage and family relationships.
- For the Task and Finish Group to work closely with partners to advise/make evidence based conclusions and recommendations to reduce the high rate of infant mortality in Luton.
- To look at areas for improvement using best practice of similar local authorities such as Birmingham and Wolverhampton.

4. EXPECTED OUTCOMES

4.1 The outcomes expected are set out below:

- That Luton Borough Council and its National Health Service Partners have clearly identified strategies that would help reduce the infant mortality rate in Luton.
- That there is greater awareness of the causes of the high rate of infant mortality in Luton.
- That the Task and Finish Group produced evidenced based conclusions and recommendations to the Executive and/or NHS Partners on the causes of Luton's high rate of Infant Mortality and actions required to reduce the rate.
- General risks and budget constraints affecting the plan to reduce IMR in Luton to have been identified and recommendations made to address them.

5. METHODOLOGY

5.1 Representatives from Luton Clinical Commissioning Group (LCCG), Luton & Dunstable (L&D) Hospital (Maternity and Paediatrics Services), Cambridgeshire Community Service (Health Visiting Services, Community Paediatrics) (CCS), Child Death and Overview Panel (CDOP), Bedfordshire University (Health and Research Department), Luton Borough Council (LBC) Public Health, Children Services, Social Justice, Communication and Consultation actively supported the review by providing information, expert advice and personal contributions at meetings of the Group.

5.2 A member of the former Local Involvement Network (LINk), now Healthwatch Luton, was co-opted on the Group.

5.3 The review received input from Bradford's Public Health using Bradford as a model of best practice.

5.4 A number of guidance/ strategy documents/ reports were reviewed and these provided background information. These are listed below;

- NHS Implementation Plan for Reducing Health Inequalities in Infant Mortality;
- Department of Health – Tackling Health Inequalities in Infant and Maternal Health Mortality Paper;
- Office of National Statistics (ONS) – Statistical Bulletin – Gestation – Specific infant mortality in England and Wales, 2010- 2012);
- Child Death and Overview Process Panel (CDOP) Annual Reports 2010 – 2012);
- Luton Joint Strategic Needs Assessment – (JSNA, 2011);
- Luton Partnership Strategy to reduce health inequalities 2010-2026;
- Family Poverty Strategy, 2011-2014;
- Born in Bradford Study, 2013;
- Every Baby Matters Bradford, March 2013;
- Conference Report on Raising awareness of genetics among culturally diverse communities May 2012- supported by NHS Airedale, Bradford and Leeds – Health Partnership project;
- Bradford Community Genetics Project – Progress Report August 2012;
- Infant deaths in Kirklees – 2002 – 2008.

5.5 Public engagement was undertaken through a press release, which generated wide public debate on the subject with particular reference to consanguinity in the town. Two local radio interviews took place with the Director of Public Health and the Chair of Luton Scrutiny Health and Social Care Review Group (HSCRG). The review topic

was also covered in the Luton on Sunday and Luton News. Interest was also shown from the BBC Asian Radio Network who aired a radio debate on 2nd May 2013 and this also generated quite a contentious debate. It was clear from the interviews held, the radio debates and news paper publications that there were mixed views and divided opinions on the issue of consanguinity within some communities.

5.6 One of the main objectives which the T&FG set out to achieve was to engage with local communities to address the issues around infant mortality and possible links to health inequalities, lifestyle, deprivation and poverty, including genetic anomalies as a result of consanguinity.

However, at the start of the review, due to the complex nature and lack of public knowledge surrounding the topic review, the Council's Consultation and Engagement advised that it was best to carry out an awareness raising campaign around infant mortality in general at the end of the review rather than the beginning, to highlight the key findings and factors that increase the risks of infant deaths.

5.7 The awareness raising campaign would set the scene for the public to understand that the issues around infant mortality as well as genetic anomalies as a result of consanguinity were a key priority for the Council. It was essential for the Council to adopt a more holistic approach of full engagement to help residents to understand what the issues were amongst the different communities in Luton.

6. SUMMARY OF FINDINGS

6.1 The T&FG considered a number of existing documents and evidence from health partners and health experts and acknowledged the following;

a) That the evidence suggests that the high rates of infant mortality in Luton are affected by a wide range of factors;

b) That there is significant evidence that the high rate of infant mortality in Luton can be partly attributable to genetic anomalies as a result of consanguinity; therefore, there is need for health partners to raise awareness in the community to help people make informed choices;

c) That along with the rest of the UK, infant deaths are reducing in Luton; It is acknowledged that there is already an action plan, but there is a need to constantly refresh the action plan to ensure its robustness;

d) That the existing work of the Council's Public Health and stakeholders to reduce infant mortality in Luton is acknowledged. However, the need for more detailed information on some of the issues would support this work.

7. THE EVIDENCE

7.1 KEY AREAS/WORK STREAMS EXAMINED

The Task and Finish Group met on 7 occasions between March and October 2013 to consider evidence from Luton Borough Council officers, and external partners which include Luton and Dunstable Hospital Maternity and Paediatrics Services, Child Death Overview Process Panel (CDOP), Luton Clinical Commissioning Group (LCCG), Cambridgeshire Community Services (CCS) and Research Fellows from the University of Bedfordshire.

The Task and Finish Group also gathered evidence outside of formal meetings to consider research papers from other local authorities as potential models of best practice, including results of investigation of infant mortality from Bradford Public Health. The Task and Finish Group mapped out the following keys areas and work streams in order to address the challenges around infant deaths in Luton:

- **Areas of deprivation; (Work stream i)**
- **Contributory factors and causes of infant mortality; (Work stream ii)**
- **Previous Areas of research and current action plans, performance indicators Local IM data, sub divided to neonatal/perinatal/still births, low birth weight, etc.; (Work stream iii)**
- **Data compared to comparable areas, such as North Birmingham and Wolverhampton for best practice. (However for best practice the group opted to model Bradford as good practice due to their holistic approach in tackling infant deaths in Bradford); (Work stream iv)**

7.2 WORK PROGRAMME

The Task and Finish Group sought to understand the key issues and pattern of infant deaths in Luton and as a starting point received a report providing an overview of infant mortality in Luton. This was to set the scene and the general context of the topic. The Task and Finish Group examined the various factors, causes and associated risks to infant mortality in Luton in order to gain an in depth knowledge of the situation. The sources of evidence considered are highlighted below:

- CDOP Annual Reports 2010/11 – 2011/12;
- Research on Genetics – Faulty Genes (Birmingham case study);
- Born in Bradford Study July 2013;
- Infant Mortality Plan – 2012 – 2015 – Luton PH;
- Infant Mortality and Luton CCG's Strategy – Luton CCG;
- Wider Determinants of Health – Luton PH;
- Key Issues relating to drugs and alcohol and link to IM – Luton PH;
- Evidence from Head of Midwifery – Maternity Service Luton & Dunstable Hospital;
- Child/Family Poverty Strategy – Luton Social Justice Section;
- Welfare Reform & Its impact – Luton Revenue Services;

- Evidence from Public Health Bradford;
- Every Baby Matter information leaflets – Bradford;
- Infant Mortality Children and Learning Perspective – Luton Children and Learning;
- Progress update on Infant Mortality Action Plan – Luton PH;
- Health visiting service provision in Antenatal and Postnatal period up to 1 year of age – Cambridgeshire Community Services.

7.3 OVERVIEW OF THE INFANT MORTALITY RATE IN LUTON

- The IMR in Luton was higher than the national average at 7.3 per 1,000 live births (2009 to 2011) against 4.4 England average. **(Paper submitted by the Assistant Director of Public Health at the T&FG meeting on 21st March 2013).** Current provisional data for Luton is 5.3 but it is unclear at this stage, what the actual gap is. The T&FG was informed that the national data is due to be published in December 2013.

- The IM rates in Luton are affected by a wide range of factors including factors linked to health inequalities, which was a greater risk in some communities. Other factors were poverty, deprivation, lifestyle and the impact of cultural and clinical issues. A major concern and contributory factor can be attributable to genetic anomalies as a result of consanguinity. The majority of infant deaths in Luton occur within the first month of life, many of these babies are very premature.

7.4 Furthermore, the T&FG heard that current data of IMR in Luton is also higher than the national average when compared to local authorities with similar demographics from 2009 to 2011. Luton figures are (10574 live births) at 7.2 with Wolverhampton at 7.3 (10545 live births) whilst Birmingham was at 7.5 (51992 live births). **(Paper submitted by the Assistant Director of Public Health at the T&FG meeting on 21st March 2013).** (Bradford figures were at 7.5 similar to Birmingham.

7.5 Current snapshot of findings – 2010 To 2012

DATE	2010 (27 children)	2011 (29 Children)	2012 (26 children)
AGE AT DEATH (ALL)	20 < 1 year of age 8 < 24 hours of which 6 extreme prematurity 5 further deaths in first week	18 < 1 year of age 5 < 24 hours of age of which all extreme prematurity) Further deaths in first week – data withheld	16 < 1 year of age 7 < 24 hours of which 4 were extreme prematurity/ 5 other cases of extreme prematurity 5 further deaths in first week
SEX (ALL)	10 boys/ 17 girls	17 boys/ 12 girls	16 boys/ 10 girls

CAUSE (LINE 1) for infants under 1 year	Prematurity/ late miscarriage/ genetics/ respiratory failure/ hypoxia/ bleed/ infection	SIDS/ Prematurity/ genetics/ hypoxia/ unascertained	Prematurity/ genetics/ SIDS/ Cardiac disease
ALL OTHER CHILDREN CAUSES	Sepsis/ cancer/ chest wound/ Neurodegenerative/ head injury/ genetic anomalies	Neurodegenerative/ infection/ congenital heart disease/ cancer/ CF/ genetics anomalies/ cerebral palsy	Organ failure/ Neuromuscular disease/ Neurodegenerative disease/ Hypoxia/ Cancer/ SC disease/ Cardiomyopathy/ Infection

7.6 There was a significant increase in deaths in 2009 (38 compared to an average of 20 in previous years), which was investigated with no pattern identified to explain the increase.

7.7 The review considered the data available and noted that although data collection was improving there was still a long way to go as statutory data does not always collect the information required. Two data sources were available and being used in Luton by Public Health; the Deaths Data and the Child Death Overview Panel data (CDOP). The Death Data in particular is cause for concern; causes of deaths are often not worded in a standardised way, no ethnicity data information is recorded and gestational age is not always completed. These data are however, collected as part of the CDOP process.

Table 2 shows the most current data for 2010-12. This shows a significant decrease in the IMR in Luton once the 2009 data was excluded. **(Source: Infant Mortality in Luton – Brief Overview Paper submitted at the T&FG meeting on 21st March 2013).**

Table 2:

Year	Number of infant deaths (<1 year)	Number of live births	IMR
2010	21	3532	5.946
2011	17	3539	4.804
2012	16	3490	4.585

7.8 Current Infant Mortality Activity in Luton

- Public Health Agreed IM Action Plan 2012 to 2013 – overseen by Children's Trust Board
- Research/ community consultation with University of Bedfordshire (UoBeds) involving community groups commenced on 12th August 2013
- Key work streams tackling performance indicators detailed in IM Profile.

8 Areas of Deprivation – Work Stream (i)

Child/Family Poverty and Welfare Reform - Council's Social Justice and Revenue

8.1 Evidence received from the Council's Social Justice departments show that rates of infant mortality are higher in more deprived wards. There were clear disparities between different areas in Luton with infant deaths rates in the more deprived areas significantly greater than the more affluent areas. Evidence heard showed that in Luton 28.4% (approximately 14,650) of children live in poverty. Also Luton's average rate of deprivation is 27% compared to the national average of 30%. Further evidence shows that there is a wide gap between the life expectancy of people living in affluent areas and people in the known deprived areas of Luton. It was found that people in the more affluent areas tend to live much longer than those in the deprived areas.

8.2 The Task and Finish Group examined further evidence and noted that the wards with the highest quartiles of infant mortality in Luton reflected some of the more deprived areas of the town.

8.3 The Task and Finish Group also looked at the impact of welfare reform, which could have adverse effect on the increasing levels of deprivation across the town. Welfare reform was seen as a big challenge for Luton and it is feared this could impact on a population that was already struggling, especially in the wards identified as the most deprived. The T&FG was informed that work around these areas meant that several measures were being introduced to address some of the likely impact of the welfare reform.

8.4 It was clear that there was a need for the Council to work more closely with stakeholders and low income households to help manage the health and general wellbeing of the people in Luton. The Task and Finish Group were mindful that due to government budget cuts and the implementation of new policies, lots of services were undergoing changes and experiencing difficult times which have an impact on the community as a whole. The indication was that families with children will be affected over and above all other households by the welfare reform as households with children were already disproportionately affected.

8.5 Evidence received show that there are significant number of families and households affected by the changes of welfare reform in Luton which could potentially impact on IM rates in Luton, although the degree of impact is not yet known. Furthermore, the T&FG was informed that work is now underway to assess the impact of the welfare reform in Luton. There were concerns that impact could be more profound in the areas of high deprivation. In 2013 spending on services to deal with the consequences of child poverty nationally rose from £12 billion to £15 billion.

8.6 The Task and Finish Group heard that gestational age and low birth weight is closely associated with infant deaths and in some cases chronic diseases in later life. The

review further noted that low birth weight is on average 130 grams lower in children from social classes IV (partly skilled occupations) and V (unskilled occupations) and babies born to families in poverty are at greater risk of infant deaths.

8.7 Evidence received on the Joint Strategic Needs Assessment (JSNA) showed that some good progress had been achieved in terms of recommendations to address issues around family poverty but there are limitations regarding government funding. Unfortunately, in the light of the introduction of welfare reform, there could be some negative effects on the work already achieved.

8.8 The Task and Finish Group recognises the importance of the Family Poverty Strategy especially its relevance to infant mortality in terms of its vision, aims and objectives, however, in the light of government cuts and policy changes there is a need to review the vision of the strategy and to include infant mortality element in particular.

The constant changes to government policy means that it was becoming more difficult to avoid negative impacts to low income households and most importantly those with children.

8.9 With regards to the work already achieved on the potential impact of welfare reform on infant mortality, family poverty and deprivation, etc, the review was informed that a Welfare Reform (WR) Partnership Board had been set up, led by Luton Borough Council (LBC) with Luton Clinical Commissioning Group (LCCG), Job Centre Plus (JCP), etc, to consider the impact of welfare reform and to work together to develop strategies to keep abreast of the situation.

> ***"there are plans for Public Health to look at the potential implication of the wider impact of the welfare reforms for Luton". (The Director of Public Health giving evidence at the Task and Finish Group meeting held on 7th August 2013)***

8.10 The links between poverty and poor health outcomes for children are both profound and inextricable; Child poverty is a cause of ill health and the relationship between poverty and health is complex and difficult to ascertain. There is a general understanding that the welfare reforms will bring about enormous changes and could determine how many people would live their lives from now onwards, but it is acknowledged that it was still at an early stage of being rolled out.

8.11 The negative effects of child poverty on health start as early before birth through exposure by the mother to smoking, stress, poor nutrition, obesity, etc,. Children born to mothers living in poverty are at an increased risk of being born prematurely, having a lower birth weight, and dying of sudden infant death syndrome(SIDS).

Recommendations/ Action		Agencies Involved	Lead Agency
1	That the Executive commends the efforts of officers in Public Health, Social Justice and Partners in investigating key issues around welfare reform, but are recommended to work jointly with partners to identify the impact of the welfare reform on infant mortality to ensure appropriate steps are taken to minimise its impact on the Luton population. **(Paragraph 8.8)** **Action Required**: All services to note and continue with current initiatives of work stream integration to identify the impact of welfare reform and target specific groups most impacted by risk of infant mortality in the deprived wards.	• **Public Health** • **LBC Social Justice** • **Luton CCG** • **LBC – Revenue, Benefits and Customer Services**	• **Public Health** • **Luton CCG**
2	That the Executive instructs the Director of Public Health to review the Family Poverty Strategy to establish links between the effects of poverty on infant mortality. **(Paragraph 8.9)** **Action Required**: That a report of any links between the Family Poverty Strategy, and Infant Mortality, be reported to the Health and Social Care Review Group for comments.	• **Public Health**	• **Public Health**

9 Contributory Factors and Causes of Infant Mortality - Work Stream (ii)

Evidence from Council's Public Health
CDOP (Child Death Review Process) Annual Reports 2010 - 12
Paper on Wider Determinants of Health
Key Issues Relating to Drugs and Alcohol and Link to Infant Mortality

9.1 Evidence heard from the Director of Public Health on the Child Death Overview (CDOP) Process Annual report 2010/12 highlighted key issues around the causes and factors of infant mortality and associated risk. The CDOP has proved helpful in providing details on child deaths and ensuring that plans are in place to tackle the risks associated with child deaths.

> **"*The Child Death and Overview Process Panel looks broadly at available information about the child to determine any modifiable factors (i) which may have contributed to the child's death and which by means of local or national intervention could be modified to reduce risk of future child deaths*" *The CDOP ensures action plans were developed to tackle the risk associated with child deaths, including issues such as smoking in pregnancy, maternal obesity, sudden deaths in infancy, hereditary conditions, etc.* (The Director of Public Health giving evidence at the *Task and Finish Group meeting held on 2nd May 2013)***

(i) (A modifiable death is defined as where there are factors which may have contributed to the death. These factors are defined as those which, by means of nationally or locally achievable interventions, could be modified to reduce the risk of future child deaths **(source: Department for Education Statistical Release – 18th July 2013)**

9.2 From the CDOP 2010/11 annual reports, the review noted that consanguinity is recognised as a significant contributory factor to infant mortality in Luton as shown through its findings. However, Public Health recognised that there are notable gaps in the information regarding consanguinity in Luton that need to be filled to inform targeted interventions such as:

- The number of consanguineous relationships in the south Asian and other communities such as travellers and Irish community;
- The degree of consanguinity between the partners in the relationship and whether the risk of infant mortality is linked and there is a strong genetic risk of autosomal recessive conditions within extended families.

9.3 The Task and Finish Group examined thoroughly the information on data as evidenced in the CDOP annual reports, 2010 to 2012 which showed that 45% of 33 child deaths reviewed in 2010-2011 were children from Pakistani origin of which 80% were under the age of 1 year of age. 12% of those were White British. Furthermore, in 2011-2012, of the 22 cases reviewed 50% of children were of Pakistani origin whilst 22% were White British. However, it was still difficult to draw real conclusions using the data available due to gaps in the information captured on consanguinity as acknowledged by health partners.

9.4 Also the Task and Finish Group wish to note the significantly higher death rates in male children reported at 82% of all the children who died during the period 2011 – 2012. It appeared that 28% of these male deaths may be attributed to genetic anomalies as a result of consanguinity. 11% of the deaths were sudden unexpected deaths in Infancy. The data suggested an overrepresentation of male deaths in Luton and the T&FG were informed that this had been audited.

(Although this was outside the remits of the T&FG review, it was felt that the findings of this audit be reported to the scrutiny Health and Social Group at a future meeting).

The review further notes the limitation in data collection:
Due to the national requirement for authorisation of access and use of data, it was not possible to have access to individual data or small numbers as the detail of this could mean that a child could be identified.

9.5 In 2010 and 2011 the number of infant deaths reduced significantly to 21 and 17 deaths respectively. The high increase in infant deaths in 2009 continued to have an

effect on infant mortality rates for the year which included 2009 as part of the pooled data.

9.6 The review further identified other associated risks from national data closely linked to infant mortality as follows;

- **Health Inequalities; Greater risk in some communities**
- **Poverty**
- **Deprivation**
- **Impact of cultural issues**
- **Risks associated with age of mother; very young and older mothers**
- **Risk associated with co-sleeping arrangements**
- **Lifestyle Factors such as**;
    - Smoking
    - Alcohol
    - Maternal Obesity
    - Drug Misuse;
- **Wider determinants of health namely;**
    - Income
    - Housing
    - Employment
    - Health deprivation and Disability
    - Education Skills and Training
    - Barriers to Housing and Services
    - Crime
    - Living Environment
- **Clinical Issues as follows;**
    - Premature births/gestational age
    - LBW/ - Low Birth Weight
    - Genetics
    - SIDS – (Sudden Infant Death Syndrome) **(SIDS and the process for investigation was excluded from this review as mapped out in the scope) Although it is acknowledged it is a cause of infant deaths.**
    - Others including uptake of immunisation, breastfeeding initiation, antenatal assessment by 12 weeks, maternal obesity, etc.

9.7 Luton 3 Year Data Analysis – Between April 2008 and March 2011 a total of 98 Luton child deaths were reported. 39% of these were neonatal deaths with many dying in the first hours or days of life from complications of prematurity and known anomalies but where the parents had opted to continue with the pregnancy. In total almost 66% of all deaths reported were in children under the age of 1 year. **Of the total deaths reviewed to date from April 2009 to March 2011 consanguinity was a modifiable factor identified in 20% of the deaths reported in Luton.**

9.8 The Task and Finish Group strongly felt that there was need for the Councils Public Health and health partners to take practical steps to minimise the risk factors associated with infant deaths in Luton but especially the disproportionately high number of infant deaths associated in the British Pakistani community, at 50% of the

total even though the British Pakistani population of Luton is 18.5%. It was noted that these deaths were caused by a number of factors. Whilst there is evidence and an acknowledgement that the percentage of deaths amongst this community is significantly higher and may be associated to consanguinity, there is need to continue to monitor the collection of data for accuracy and to help draw informed conclusions directly relevant to infant deaths. This would help to identify the high risk areas and the most vulnerable.

(The Director of Public Health at an interview with Beds, Herts & Bucks on 2nd May 2013, stated:) **"Public Health is looking at genetic conditions in the same way as other health risk for infant mortality, such as smoking in pregnancy and maternal obesity, and making sure the right services were available". She further stated, "We are working with the screening and genetic counselling service, to make sure they have tailored information to meet the particular health needs of Luton's population."**

9.9 Evidence received from Public Health on the wider determinants of health and link to infant mortality suggest that there had been less of a specific focus around the wider determinants of health in relation to infant mortality. This was also the case for drugs and alcohol and its impact on infant mortality.

9.10 **(Quote)**

"in terms of the IM Strategy and Action plan, there were minimal actions around the wider determinants. However, there were plans to look at the impact of the wider determinants of health on infant mortality and recently Public Health had been involved in issues such as housing and how the housing strategy could be developed to take into account impact on families in deprived areas". ***(The Assistant Director of Public Health giving evidence to the Task and Finish Group meeting on 4th June 2013)***

9.11 The Task and Finish Group noted that congenital anomalies are a significant cause of infant deaths in Luton. The risk of congenital anomalies is double that for couples in a consanguineous relationship compared to non-consanguineous couples. The University of Bedfordshire is currently carrying out targeted research and engagement work on genetic anomalies in identified risk communities in Luton commissioned by Public Health. The engagement aims to understand community perceptions and identify effective methods to inform communities about risk and access to services.

"Reducing infant mortality is priority for Luton Borough Council and we are currently working with the University of Bedfordshire and making arrangements to carry out targeted engagement and consultation to identify the most effective way to deliver key public health information regarding risk reduction to individuals and communities. In line with how we commission services this work will seek local views on how the current service provision can be improved to support this priority". (The Assistant Director of Public Health Luton in response to a press enquiry on 4th June 2013)

9.12 The T&FG also heard evidence on the issue of generational consanguinity. Evidence indicates that consanguinity increases the risk of infant mortality and further evidence suggest an increased risk from generational consanguinity in terms of people's attitudes and beliefs. There is a need to ensure that people are well aware and informed of the risk involved and what options they have to help make informed decisions.

" We are making sure people have the right information upon which to make their decisions, and we are working with the screening and genetic counselling service, to make sure they have tailored information to meet the particular health needs of Luton's population… it was not about making judgements about people's behaviour but the Council had a responsibility to try and improve the health of the town's population". (The Director of Public Health at an interview with Beds Hearts & Bucks on 2nd May 2013)

"Clinical Director for Paediatrics L&D Hospital, stated "there was a compound effect and the risk of having a child with faulty genes becomes higher and this was not just relevant to Pakistani families as there were other BME who practice consanguinity....."The debate should not be about branding; it should be more about supporting and helping people who are vulnerable. There is the need to be cautious and sensitive when relating bad news specifically around infants' deaths and genetic anomalies" (Task and Finish Group meeting held on 4th June)

9.13 The Born in Bradford study funded by the National Institute for Health Research under the Collaboration for Leadership in Applied Health Research and Care programme is the largest of its type ever conducted. It examined detailed information collected about more than 11,300 babies involved in the Born in Bradford (BiB) project a unique long term study following the health of babies who were born in the city at Bradford Royal Infirmary between 2007 and 2011. The research team found

that the overall rate of birth defects in the BiB babies was approximately 3% nearly double the national average at 1.7% in England and Wales.

"Geneticist and lead author D. Eamonn Sheridan – University of Leeds says "the vast majority of babies born to couples who are blood relatives are absolutely fine, and whilst consanguineous marriage increases the risk of births defect from 3% to 6%, the absolute risk is still small and that consanguinity only accounts for a third of birth defects". (source: Born in Bradford study – The Times Newspaper 4th July 2013)

The level of risk of children born with congenital anomalies depends on the degree of relationship of the parents. The risk of congenital/genetic disorders and early mortality is 2-8% and approximately 4% respectively, at least double the risk of children born to unrelated parents. Evidence further showed that British Pakistani women are 13 times more likely to have children with recessive disorder affecting a child. But many of these autosomal recessive conditions may not yet have manifested themselves in the wider family and may come as a shock to the family. In Luton, 25% of births in 2009 were babies born to Pakistani mothers. **(Source: Luton Joint Strategic Needs Assessment (JSNA) 2011.**

Although the Born In Bradford (BiB) research is of particular importance to Bradford because of the characteristics of its population, its finding are of relevance to other areas of the UK where consanguineous marriage is a cultural norm, such as Luton. It is important that couples are aware of any risk so that they can make informed choices when planning their families.

Birmingham Primary Care Trust (PCT) estimates that one in ten of all children born to first cousin marriages in Birmingham's large Pakistani community either dies in infancy or goes on to experience an impairment as a result of recessive genetic conditions. (source: Ethnicity and Inequalities in Health and Social Care, Vol. 5 Iss: 2 pp. 43-51 Emerald Article: Faulty gene: Consanguinity in the Pakistani community)

Recommendations/ Action		Agencies Involved	Lead Agency
3	The Task and Finish Group acknowledges that data collation on the Infant mortality Rate (IMR) has improved in the last few years, since CDOP was set up in 2008. However, the Executive request the Director of Public Health to continue to take all necessary steps to improve data collection and analysis and ensure relevant information on IMR is easier to assess. The IM data from the deaths database should be used in conjunction with the CDOP data as this generates a more detailed picture of the death and associated risk. **(Paragraph 9.2)**	• Public Health • CDOP • Luton CCG	• **Public Health** • **CDOP**

Recommendations/ Action		Agencies Involved	Lead Agency
	Action Required That the Director of Public Health be instructed to continue to take the necessary steps to improve IMR data collection and analysis to ensure results of the analysis are easier to assess.		
4	That the Executive requests the Director of Public Health to submit a report on the findings of the audit of gender imbalance of 2011/12 infant mortality to the Health and Social Care Review Group. **(Paragraph 9.4)** **Action Required:** Report on the audit of gender imbalance findings to be submitted to the Health and Social Care Review Group by the Director of Public Health.	• **CDOP** • **Public Health**	• **Public Health**
5	That the Luton Clinical Commissioning Group (LCCG) be requested to ensure genetic screening is made more accessible and Public Health to raise awareness amongst health professional and the public to increase uptake with a focus on education and general engagement on the issue through religious leaders in the community. **(Paragraph 9.8)** **Action Required:** **(i) The LCCG should Commission** **(ii) Public Health to promote** That Public Health encourages schools and health partners to work together with communities and faith groups to encourage greater awareness of and uptake of genetic screening.	• **LCCG** • **Public Health**	• **LCCG** • **Public Health**
6	The Task and Finish Group commends and recognises the research work on genetics already being commissioned with the University of Bedfordshire and recommends that the research findings are used to influence the Council's policies and other health agencies to engage the community on the issue of genetics in general but also with a clear focus on consanguinity. **(Paragraph 9.11)** **Action Required:** That the Director of Public Health use the findings on genetics to inform best practice to be communicated to religious groups, schools, agencies, etc.	• **Public Health** • **UoB**	• **Public Health** • **UoB**

Recommendations/ Action		Agencies Involved	Lead Agency
7	That the Executive request the Director of Public Health to continue to improve community engagement to explore options and ways to address infant mortality and this be communicated in ways that best meet the needs of the local community. **(Paragraph 9.12)** **Action Required:** (a) That the Director of Public Health encourages commissioners to ensure that local need to reduce infant mortality through training and service provision by maternity, general practice and early years health professionals including health visitors and children centre staff with skills to inform women at increased risk of infant mortality in a sensitive, supportive and helpful manner. (b) That the Director of Public Health ensures increased joint working with stakeholders through the "Better Together" agenda to communicate this message further.	• **Public Health**	• **Public Health**

10 <u>Previous Areas of research and current action plans, performance indicators Local IM data, sub divided to neonatal / perinatal / still births / low birth weight – Work Stream (iii)</u>

Research Team University of Bedfordshire
Research on genetic faulty genes
IM Action Plan 2012 – 2015 (Public Health)

10.1 Evidence was received from the Council's Public Health, Luton Clinical Commissioning Group, University of Bedfordshire and the Maternity Service of Luton and Dunstable Hospital to enable the review consider previous areas of research and current action plans, performance indicators local IM data, sub divided to neonatal/perinatal/and low birth weight.

10.2 The T&FG considered in detail generational attitudes and beliefs towards consanguineous marriages and examined evidence from the University of Bedfordshire in order to gain insight and better understanding in this area. Further evidence was presented by University of Bedfordshire on a major area of research on faulty genes and genetic anomalies using research commissioned in Birmingham in 2007. The T&FG was further informed that Birmingham research was carried out by the same researcher now working with the University of Bedfordshire and commissioned by LBC PH to carry out local research and engagement.

10.3 The Birmingham research on faulty genes shows that genetic anomalies as a result of consanguinity are recognised as a significant contributory factor to infant mortality. Evidence received indicates that the infant mortality rate in Birmingham is above the national average and the gap was increasing whilst the infant mortality rate had fallen in other parts of the West Midlands and across the country as a whole, including Luton. Significantly, the infant mortality rate in Birmingham had increased by 13% for some communities.

This significant increase was rightly acknowledged by Birmingham Health and Wellbeing who commissioned the Birmingham research as a significant challenge to take remedial action. A deeper analysis is required as the reasons for increase are not yet fully understood. A qualitative approach was used to explore attitudes and beliefs towards consanguineous marriages and health amongst the Pakistani/Kashmiri community in Birmingham. This approach focused on inter-generational and gender similarities and differences as a way of planning and developing future maternity provision in Birmingham.

10.4 There were several reasons that prompted the research including:

- Need to explore general awareness and risk perceptions associated with consanguinity;
- Need to investigate inter-generational and gender similarities and differences in attitudes, beliefs and expectations of consanguineous marriages;
- Need to inform the Birmingham Health and Wellbeing Partnership (BHWP) on ways of planning and developing future maternity provision that support members of the Pakistani community in Birmingham.

10.5 Evidence from the research in Birmingham shows that participants had a general understanding and awareness of still births and genetic conditions but had a poor understanding of genetics. Respondents were reluctant to accept the link between cousin marriages and birth issues and explanations for still births and impairments were largely attributed to the "will of God". Female respondents were in favour of screening for genetic conditions but would not terminate pregnancies as this was contrary to Islamic ideas about pre-destiny. Furthermore, all respondents wanted more information on cousin marriage and how it is linked to disabilities. ***(Dr. Nasreen Ali (Research Fellow from the University of Bedfordshire) giving evidence at the Task and Finish Group meeting on 4th June 2013).***

The T&FG heard that participants were suspicious around the topic and the available statistics which illustrated that consanguinity led to an increased risk of still births and malformations. The research shows that there was a general understanding from the community that "rates of still births and disabilities were not seen to be significantly higher among the Pakistani community in Birmingham or nationally when compared to the white majority or other ethnic minority in the community". What came across was that there is a clear need to improve health outcomes and increase awareness of the causes of infant deaths.

10.6 From the research, there was an indication that some participants believed that the higher rates of pregnancies and births within the BME community increased the

chances of having children with disabilities or children with faulty genes due to a higher number of pregnancies and births rates.

10. 7 Furthermore, some of the participants and respondents argue that debates on consanguinity and the research on genetic anomalies were a direct attack on the Muslim marriage system and a poorly disguised aggression towards the Islamic way of life. They argued that assisted marriages to cousins marked them as being unique from the majority of the white community and other non Muslim settlers.

10.8 The Task and Finish Group noted the implication for practice from the Birmingham research and concluded that there was need to take actions that would facilitate and increase understanding about cousin marriage and link to genetic anomalies. There was a need to adopt the Birmingham's qualitative approach in order to explore attitudes and beliefs towards consanguineous relationships. As in the Birmingham approach, Luton should also adopt an approach to focus on inter-generational and gender similarities and differences in order to develop future maternity provision in the town. Also as evidenced through the Birmingham findings, there is a need to generate the debate which puts medical issues/questions within a moral and ethical and sensitive conversations. The T&FG heard that this was underway as part of the research commissioned from the UoB.

The T&FG were advised that there were plans for the NHS in Luton to work jointly with health partners to develop a system that would help understand the intergenerational attitudes and beliefs towards consanguineous relationships, including the general awareness and risk perceptions and to openly discuss these sensitive issues.

Council's Public Health

10.9 The Infant Mortality Action Plan for Luton was also submitted as evidence in June 2013 and a further progress update was submitted to the Task and Finish Group meeting on 11th September 2013.

10.10 The T&FG received evidence on the number of neonatal deaths in Luton as a result of congenital anomalies. During the period 1st April 2011 to 31st March 2012, a total of 11 neonatal deaths (deaths occurring during the first 28 days of life) were reported for babies whose parents live in Luton. 54% of these babies died within the first few hours of life either from complications of extreme prematurity or as a result of known congenital anomalies, where parents had chosen to continue with the pregnancy.

10.11 Further evidence shows that 42% (10) of the deaths recorded during 2011-2012 were said to be British Pakistani ethnicity (compared to 12% of the population from this BME community).

10.12 The IM Action plan submitted to the group in June 2013 highlighted the following key messages;

- Greater Multi-agency partnership working

- Learning from other areas with a comparable IM rate to share good practice, however recognising that there is no template and one size fits all.
- Dynamic implementation, as new information is generated the plan needs to be revised and updated to reflect changes and emerging risks.
- Communicate or engage effectively and sensitively with individual families and communities.
- Patience. There is no quick fix, this is a long term plan to improve IM in Luton and while there are service improvements that can be commissioned quickly, generational changes, understanding and discussing opinions regarding cultural norms is a long term commitment.

10.13 The Task and Finish Group noted that there was ongoing implementation to complete actions and monitor key performance indicators (KPI) and look at joint working to improve IM in Luton as part of transition. The review commended the work already in progress but emphasised the need to continue to work jointly and report on the progress of action plans and implementation to the Scrutiny Health and Social Care Review Group. The need for more data has been recognised.

10.14 A progress update on the Infant Mortality Action Plan was reported to the T&FG in September. The need to continuously refresh the IM Action Plan comparing Luton with other local authorities for best practice was reiterated. Furthermore, the current provisional data indicates that Luton's IMR for 2010-12 has reduced to 5.3 per 1,000 live births (pending published data in 2013) from 7.2 in 2009-11 with a difference of 22 fewer infant deaths in the three years period of 2010-12 compared to 2009-11.

Evidence: Luton Clinical Commissioning Group (CCG), Maternity Services Luton and Dunstable Hospital & Cambridgeshire Community Services

10.15 In regards to effective working and capturing feedback to improve service needs, evidence received shows that in line with health service transition and the emergence of new organisations there is a revision of governance arrangements with an Infant Mortality (IM) Group to now report to the Child Health Strategy Group (CHSG). The CHSG reports via the Children's Trust Board to the Health and Wellbeing Board.

10.16 Whilst evidence received from the Head of Midwifery at the Luton and Dunstable Hospital Maternity Service and the CCG shows a robust and effective system of reporting incidents, investigations and reviews, there is a need to continue focus on capturing feedback for a continuous open and honest incidence reporting. This will help to deal with concerns before they become issues and help to highlight where service improvements can be made.

It was reported that the Maternity Service previously had a user group (Maternity Services Liaison Committee (MSLC)) which disbanded. The LCCG responsible for establishing the group is currently working with the L&D to re-establishing the MSLC. The T&FG supported the need to re-establish and review this group to improve service provision.

10.17 Further evidence received from the Luton Clinical Commissioning Group shows that the Commission's outcome goals are completely aligned with the three strategic

priorities articulated in the Luton Joint Health and Wellbeing Strategy. The first being *"every child and young person has a healthy start in life".* Further evidence received shows that although it is difficult to assess progress against this priority, the CCG has selected the measure of infant mortality rate as the overarching barometer of progress. It was articulated that health in later life is strongly influenced by childhood experiences and ensuring a healthy start at an early stage would improve a child's health and that of the whole family.

"Tackling infant mortality was a joint working partnership between the local authority, health services and health partners including Luton Clinical Commissioning Group. The target set by the CCG is to reduce infant mortality per 1,000 births from a baseline of 7.5 to 5.3 by 2014-15" ***Dr. Alabi Clinical Chair, GP and Clinical Director for Children and Young People – Luton CCG – giving evidence at the Task and Finish Group meeting on 11th July 2013.***

As part of the strategy of LCCG the aim is to reduce the incidence of infant mortality in Luton. To support this work the focus is to improve overall health such as improved maternity commissioning and developing a model to address consanguinity with health care professionals and community groups. There were also plans to create a pathway for parent's pre/post conception to access genetic screening and to increase antenatal and new born screening uptake, and increasing uptake of healthy start vitamins, etc. The T&FG recognised the need to develop a workable programme that would help achieve this outcome and that it should be reflected in the IM plan.

10.18 As a follow up to the evidence received from the Midwifery and Maternity Services, Luton and Dunstable Hospital, the T&FG was keen to hear from the Cambridgeshire Community Service - Health Visitor Team to find out what other support was available after discharge from hospital.

Evidence received shows that support offered by the heath visitors commenced between 10 –14 days post-delivery with a new birth visit to all mothers. This home visit includes assessment of maternal mental health, the child's first month of life, child's feeding, promoting sensitive parenting, development, safety and prevention of sudden infant death, identification of prolonged jaundice and or health issues and safeguarding.

The T&FG heard that the current level of staffing is 29.96 WTE, but the review was pleased to note that there were plans to increase staffing levels to 70 WTE Health Visitors as a staged implementation of the DH Call to Action. This would improve capacity in enabling women to receive more support in the community. **(Evidence from the Health Visiting Service CCS Luton Locality at the T&FG meeting on 14th October 2013)**

However, it was noted that information sharing in relation to data protection across the board was a challenge. There was a need for a clearer pathway of information and support mechanism to ensure consistency and robustness of information across all agencies.

10. 19 The evidence received shows that various health groups including the Council's Public Health, Midwives and Health Visitors, Luton Clinical Commissioning Group,

etc, work closely with women of various ages, and parents. The T&FG recognised that it would be useful for services to look at evaluating the effectiveness of messages being communicated to vulnerable groups, including young mothers and looked after children. However as this information was not requested during the evidence gathering process, the T&FG felt that there was need for evidence to be submitted to a future meeting of the Scrutiny; Health and Social Care Review Group to show that this was already in place. Where evaluation of the process was not currently in place, it is recommended for the Director of Public Health to carry out a piece of work to monitor and evaluate the effectiveness of messages communicated to vulnerable groups in the community.

Recommendations/ Action		Agencies Involved	Lead Agency
8	**Recommendation 8 – (Paragraph 10.8)** That the Executive request the Director of Public Health and health partners to organise an awareness raising campaign to inform people how to manage the associated risk of infant mortality to ensure continued reduction in the high rates of infant mortality. **Action Required:** (a) That a public resource document be developed explaining risk factors and risk minimisation to be accessible to families to tie into the awareness campaign; provide advice and tools to educated people in family planning, recognise lifestyle behaviours that impact on child health and signpost families to health support including families who may have increase risk of children with disabilities related to genetic conditions. (b) That the Director of Public Health and University of Bedfordshire use existing mechanisms such as community engagement programmes in order to engage with all Luton residents as well as hard to reach groups, ensuring community involvement at all levels. (c) That the Director of Public Health and health partners continue to raise awareness to address intergenerational attitudes and beliefs towards consanguineous relationships to openly discuss these sensitive issues	• Public Health • LCCG • NHS Midwifery and Maternity Services • Cambridgeshire Community Services	• **Public Health**
9	That the Executive request the Director of Public Health to continue to refresh and update the Infant Mortality Action Plan to ensure dynamic implementation and the inclusion of emerging risks in particular, the inclusion of the Child Poverty Strategy element. **(Paragraph 10.12)**	• Public Health • Social Justice	• Public Health

Recommendations/ Action		Agencies Involved	Lead Agency
	Action Required: (a) That the Infant Mortality Action Plan reflect the longer term effort needed on wider causes of infant mortality including child poverty, reducing the gap in educational attainment and improving employment opportunities in Luton. (b) That work take place with the CDOP to generate more information on wider determinants impact (as appropriate) on each infant death investigated.		
10	That the Luton Clinical Commissioning Group (LCCG) consider re-establishing a patient and staff User Group for Maternity Services to encourage feedback to help identify issues and to help early intervention and prevention of incidents for continued service improvements. **(Paragraph 10.16)** **Action Required:** To re-establish a system to encourage and record patient and staff feedback, to help identify and address issues in a timely manner.	• LCCG • L&D Maternity Midwifery Service	• LCCG • L&D Maternity Midwifery Service
11	That the Executive request the Director of Public Health to set up an awareness raising programme on infant mortality risk factors throughout the borough to encourage women and their families to consider personal lifestyle choices, including reducing smoking, alcohol and substance misuse and maintaining a healthy lifestyle. **(Paragraph 10.17)** **Action Required:** That awareness raising programmes be strengthened to focus on women with health and social needs, including those whose health behaviours indicate particular vulnerability and women living in localities and in communities with higher infant mortality. Those groups as well as any other identified as part of the dynamic information collection should be prioritised for support, including close working between midwifery and family support systems.	• Public Health • LCCG	• Public Health • LCCG
12	That the Executive request the Director of Public Health to work with health partners including LCCG and Luton Local Healthwatch to carry out a consultation or survey which would evaluate the effectiveness of messages being communicated to those who require specialist support and or vulnerable groups. **(Paragraph 10.19)** **Action required:** To carry out a consultation or survey which fully	• Public Health • Luton CCG • Local Healthwatch • CCS	• Public Health

Recommendations/ Action		Agencies Involved	Lead Agency
	evaluates the effectiveness of health messages communicated to all vulnerable groups.		

11 Data Compared to Comparable areas, using Bradford as Best Practice Authority– Work Stream (iv)

Research Team University of Bedfordshire & Evidence from Bradford and Birmingham study.

11.1 The Task and Finish Group considered papers and evidence from Birmingham which has similar demographics to Luton and found that the infant mortality rate in Birmingham (7.6 per 1,000 live births) is significantly higher than the England rate (4.6 per 1,000 live births) and had gone up by 13% in the last few years.

11. 2 The Task and Finish Group further considered papers from Bradford which also has similar demographics to Luton and found that there was evidence that although Bradford's infant mortality was much higher than national average at 8.2 between 2006 to 2008, there has been a steady improvement from 2009 to 2011. Bradford's current infant mortality rate has reduced to 7.5 which follow a year on year downward trend for the last five years.

11.3 Following the Bradford investigation, actions to improve health and reduce risk of infant deaths were set out and achieved. Some of the actions such as baby friendly breastfeeding initiatives, Vitamin D campaigns and health start programmes, smoking in pregnancy (carbon monoxide monitors introduced), are also been delivered by Luton. However, Luton was yet to deliver on the following actions;

Nutrition guidelines published
Genetic Inheritance awareness raising campaigns
Born in Bradford campaigns

11.4 The T&FG also recognised the need for the Director of Public Health to consider the wider social determinants of health of those in consanguineous relationships in order to ensure that the right services are made available and to provide the right support to all groups.

11.5 The Task and Finish Group heard that there was currently no local profile on the number of close relative marriages in Luton available and that genetics was a lot more complicated than just recording whether people were married to either their first cousin or second cousins. The review felt that this was an area that should be looked into in order to create a clearer picture of the data and statistics in Luton.

11.6 Lessons from the Birmingham study;

- Termination of pregnancies was not considered an option within certain communities and religious groups
- Mixed feelings about the debate as number of people said they would accept screening but more steer was required from Islamic scholars
- Those who wanted a change where the ones who suffered loss of a child or have kids with a disability
- The attitude of health care professionals was not encouraging in most cases
- Some of the participants felt it was the them and us situation
- Lack of knowledge came across as they put it down to God's will

11.7 The Task and Finish Group acknowledged that the Bradford in depth study was very comprehensive, robust and balanced, with very positive response from the community. It is hoped that the ongoing research on genetics by the University of Bedfordshire and Luton's Public Health will give a clearer picture of the situation. It is recommended for the research on genetics to be robustly promoted to ensure maximum engagement and involvement at all levels.

Recommendations/ Advice		**Agencies Involved**	**Lead Agency**
13	That the Executive requests the Director of Public Health to widen access to the genetic counselling service in order to target pre-conceptions and give people the support they need to make informed choices. **(Paragraph 11.6)** **Action required:** The Director of Public Health produce a leaflet, similar to the 'Bradford Every Baby Matters' initiative aimed at early intervention, to send the key messages and to help engage and inform Luton residents of options which should be displayed in key contact points in Luton such as: **(i) The LCCG should Commission** **(ii) Public Health to promote** • Health Centres • Schools • GP Surgeries • Registry Offices • Council offices, etc.	• Public Health • CDOP • Luton CCG	• **Public Health** • **CDOP** • **UoB**
14	That at the conclusion of the research on genetics by the University of Bedfordshire, the Director of Public Health be requested to submit a report outlining the methodology, recruitment and sample selection process, overall results, outcomes and recommendations to the Health and Social Care Review Group for comments and input before the final report is published. **(Paragraph 11.7)** **Action required:**	• **Public Health** • **UoB** • **CDOP** • **Luton CCG**	• **Public Health** • **UoB** • **CDOP**

Recommendations/ Advice		Agencies Involved	Lead Agency
	The report should include questions asked during the investigation. Also the Council's Consultation Team should be involved to help with the study to ensure engagement from a cross section of the community.		

12. Responding to the IMR Review Group Recommendations

12.1 In accordance with health scrutiny regulations, the IMR Review Group can request responses from recipients on how they intend to deal with its report and recommendations within 28 days of receipt.

12.3 It is also a practice for such reviews to request progress reports from relevant recipients on the recommendations accepted.

12.4 As the Task and Finish Group will be dissolved after the review, initial responses and eventual progress reports are requested to be submitted to the Scrutiny: Health & Social Care Review Group.

Recommendations/ Advice		Agencies Involved	Lead Agency
15	That the Executive request the Director of Public Health, and the Luton Clinical Commissioning Group (LCCG) to respond to the Health and Social Care Review Group on the recommendations of the Infant Mortality Task and Finish Review Group within 28 days of receipt and also provide a progress report on those recommendations that are accepted to a future meeting of the Health and Social Care Review Group to be determined and included in the Committee's annual work programme. **(Paragraph 12.1)** **Action Required:** That the Director of Public Health be requested by the Executive to coordinate all partners responses to the report and recommendations to the Health and Social Care Review Group for initial response and annual reporting.	• **Council's Executive**	• **Council's Executive**
16	That the Executive is recommended to consider and approve the recommendations of the Infant Mortality Task & Finish Review Group and request the Director of Public Health to lead on and co-ordinate the implementation by all relevant agencies and provide feedback to the Scrutiny Health & Social Care Review Group as required. **(Paragraph 12.4)** **Action Required:**	• **Council's Executive**	• **Council's Executive**

Recommendations/ Advice		Agencies Involved	Lead Agency
	That the final report be submitted to the Executive, following approval by the Overview and Scrutiny Board		

CONCLUSION:

The group has absorbed a lot of evidence from health professionals and researchers on Infant Mortality in Luton. It is clear that there are two main factors behind Luton's higher than average Infant Mortality Rate: deprivation and lifestyle factors, and congenital defects due to consanguinity.

Work is underway to try and address the factors around deprivation and lifestyle. The midwifery team have set of goals aimed at delivering healthy babies. Obesity, smoking, drug and alcohol abuse will not be eradicated, but still need to be tackled as part of the wider public health campaign. The Task and Finish Group have made recommendations around partnership working for those tasked with delivering the public health agenda. However, the Task and Finish does have concerns that Welfare Reform may have an adverse effect on delivering that agenda.

Dealing with genetic issues linked to consanguinity is altogether more complex, although work has begun in this field; the genetic effects of consanguinity are far more prevalent in one community in Luton, the Pakistani/Kashmiri community. Although it is noted that this is not the only community where consanguineous relationships are known to exist, further research is required to establish the level of understanding in these communities and what action to take to reduce incidence of genetic anomalies, infant deaths and babies born with life limiting disorders. The T&FG welcome the partnership between the University of Bedfordshire and Luton Borough Council's Public Health. It is clear, however, that the solution needs to come from partnership working between statutory agencies and the community itself. Also the T&FG recognised that the Council's Public Health has a pivotal role to play in reducing infant deaths in Luton. It is obviously the case that the vast majority of children born from consanguineous relationships are not affected physically from genetic anomalies and associated health conditions and disabilities, although others not physically affected may be carriers of the disorder and at risk when they start a family. Understanding genetic risk is important for informed family planning.

It is our hope that this report stimulates debate within the community in Luton including the Pakistani/Kashmiri community on how to tackle these issues in partnership with statutory agencies.

The review of Infant Mortality is a complex and sensitive subject which was made possible by the hard work of all involved. We would like to thank all officers for their invaluable contributions. We hope the recommendations will help improve outcomes and have a positive impact on families and babies in Luton.

Trend data

Year	Luton	England and Wales
1996-98	8.0	5.9
1997-99	7.7	5.8
1998-00	8.3	5.7
1999-01	8.0	5.6
2000-02	7.8	5.4
2001-03	6.0	5.3
2002-04	6.0	5.2
2003-05	5.3	5.1
2004-06	6.2	5.0
2005-07	6.0	4.9
2006-08	6.0	4.8
2007-09	7.4	4.7
2008-10	7.5	4.5

Mortality in Infancy 2008 to 2010

	No. of live births	No. of deaths <1yr	Rate per 1000 live births	95% CI lower level	95% CI upper level	Sig diff to England
Luton	10590	79	7.5	6.0	9.3	High
Hillingdon	12525	60	4.8	3.7	6.2	Not
Redbridge	12728	62	4.9	3.8	6.2	Not
Birmingham East & North	20630	152	7.4	6.3	8.6	High
Wolverhampton City	10220	79	7.7	6.2	9.6	High
East of England	216074	864	4.0	3.7	4.3	Not
England	2030874	9260	4.6	4.5	4.7	

(Information received from the Council's Public Health in March 2013)

GLOSSARY OF TERMS AND DEFINITIONS APPENDIX 2

TERM	MEANING	DEFINITIONS
LCCG	Luton Clinical Commissioning Group	Health Commissioners in Luton
NHS	National Health Service	National Health Service
LBC	Luton Borough Council	Local Authority
CDOP	Child Death and Overview Process Panel	Body set up in 2008 with statutory responsibility to review all deaths of children and young people aged less than 18 years old.
IMR	Infant Mortality Rates	The number of deaths under the age of one year per 1,000 live births
SUDI	Sudden unexpected deaths in infancy	An unexpected death of an infant **(DH 2009, FSID 2010).**
SIDS	Sudden infant death syndrome	The sudden death of an infant, which is unexpected by history, and in which a thorough post-mortem examination fails to demonstrate an adequate cause of death **(DH 2009, FSID 2010).**
CCS	Cambridgeshire Community Service	Cambridgeshire Community Services NHS Trust: provides health services across Cambridgeshire, Peterborough, Luton and Suffolk
ONS	Office of National Statistics	Office of National Statistics
HSCRG	Health and Social Care Review Group (LBC)	Set up by the Overview and Scrutiny Board of Luton Borough Council in 2011 to oversee and scrutinise health and social care matters.
JSNA	Joint Strategic Needs Assessment	Provides a comprehensive analysis of the current and future health and wellbeing needs for adults and children in Luton.
BME	Black and Minority Ethnic	Black and Minority Ethnic
BiB	Born In Bradford	Born In Bradford is a cohort study of babies born in Bradford, and their parents:
LBW	Low Birth Weight	Baby born weighing less than 2,500 grams (or 51/2 pounds) **(Source: LBC Public Health Paper on Infant Mortality Plan submitted at the T&FG meeting on 4th June 2013)**
CHSG	Child Health Strategy Group	This is a CCG led partnership of NHS and public health focussed on the health of children in Luton.

WTE	Working Time Equivalent	Working Time Equivalent
		Neonatal Mortality Deaths during the first 28 days of life per 1,000 live births ***Consanguinity*** When both partners in a relationship are related to each other by at least one common ancestor ***Perinatal:*** Describes the period surrounding birth, and traditionally includes the time from foetal viability from about 24 weeks of pregnancy up to either 7 or 28 days of life ***Perinatal Mortality:*** Live births - deaths after 24 completed weeks of gestation and death before 7 completed days ***Congenital anomalies:*** Congenital anomalies are also known as birth defects, congenital disorders or congenital malformations are structural or functional anomalies, including metabolic disorders, which are present at the time of birth. **(Source World Health Organization - WHO)** ***Modifiable death:*** Where there are factors which may have contributed to death. These factors are defined as those which, by means of nationally or locally achievable interventions, could be modified to reduce the risk of future child deaths. **(Source: Department for Education Statistical Release, 18th July 2013)**