Why children die: death in infants, children and young people in the UK Part D

October 2014

A POLICY RESPONSE FOR SCOTLAND TO THE REPORT 'WHY CHILDREN DIE: DEATH IN INFANTS, CHILDREN AND YOUNG PEOPLE IN THE UK – PART A'

RCPCH
Royal College of
Paediatrics and Child Health
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Foreword

Maximising children's chances of survival must take priority in our society, so it is a shocking fact that despite having one of the best health systems in the world, the UK has one of the worst child mortality rates in Western Europe. *Why children die: death in infants, children and young people in the UK (Why children die)* highlights the disparity in child mortality rates across Europe, and the impact poverty and inequality have on risk of premature death during childhood. This narrative has been further emphasised in a recent series published by The Lancet, *Child death in high-income countries,* which demonstrated a persistent inverse association between socioeconomic status and childhood mortality[1].

It is therefore welcoming to see clear ambition and a joined-up approach in Scotland to improving the life chances of children and young people through *Getting it right for every child (GIRFEC)*[2] the *Children and Young People (Scotland) 2014* Act[3]*,* and the *Early Years Collaborative (EYC)*[4], embedding the health and wellbeing needs of children and young people not only in policy and practice, but in the hearts and minds of wider Scottish society. The announcement of a Scottish *Child Death Review System*[5] signals further commitment to better understanding the reasons why children die and taking action to reduce avoidable mortality.

With such a clear ambition for improving children's outcomes, however, comes both opportunity and responsibility to ensure these important legislative and policy changes are translated into tangible outcomes for reducing the number of childhood deaths. Our recommendations therefore acknowledge and build on the existing frameworks for children and young people in Scotland, emphasising key areas which are vital to childhood survival.

Specifically, we highlight the importance of health during pregnancy and early infancy, working to further reduce smoking rates and strengthen protective factors such as breastfeeding. We acknowledge the need to improve the knowledge and skills of young people to make informed decisions about their sexual and reproductive health, though measures such as compulsory Sex and Relationships education in schools. With concerning injury and self-harm mortality rates in Scotland, we also highlight the vital importance of better recognition of mental health difficulties and the provision of a well-resourced mental healthcare system which provides timely intervention and specific support to those most vulnerable. Healthcare professionals must also strive to improve the care of children with long term and potentially fatal conditions such as epilepsy, asthma and diabetes, and ensure that they have the knowledge and skills to recognise a sick child and provide timely intervention.

There is much in Scotland that can be celebrated and learned from, however we cannot be complacent when it comes to reducing avoidable mortality in children and young people. All of us have an important role to play, and we hope *Why children die* contributes to maximising this opportunity to create better outcomes for Scotland's children and young people.

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Dr Peter Fowlie, Officer for Scotland, RCPCH

Introduction

Each year approximately 350 to 450 infants, children and young people die in Scotland. Similar to figures across the UK, the majority of deaths occur in children under one year of age, with the second largest number of deaths occurring in the 15 to 18 year old age group[6]. *Why children die: death in infants, children and young people in the UK – Part A (Why children die)* argues that much can be done to reduce mortality during childhood, with poverty and inequality playing a pivotal role.

Although *Why children die* highlights specific measures the UK government must take to tackle poverty and inequality, there is much that the Scottish Government can and is doing to reduce the impact of poverty and inequality on risk of premature death. The recommendations set out in this paper therefore acknowledge the role the Scottish Government, as a result of devolved powers, can make to improving children's chances of survival.

Two key areas for action as highlighted in *Why children die,* health systems and organisations, and healthcare and public health, have been used as a framework for these policy recommendations.

Health systems and organisations

Tailoring the health system to the needs of infants, children and young people

Why children die highlights how the way we deliver healthcare, funding systems, and the emphasis on primary care can all affect the lives and health of infants, children and young people. It is vital that primary care services are able to identify children with early signs of illness and that any concerns are appropriately assessed and managed at the first point of contact[7], ensuring children and young people receive the right care at the right time, maximising their health and safety.

The *Children and Young People (Scotland) Act 2014*[3] provides a strong foundation for putting children and young people at the centre of service planning, ensuring their needs and rights are respected across health, social care and education sectors. Through the *Getting it right for every child (GIRFEC)*[2] approach there are clear opportunities to strengthen the health system in order to maximise outcomes for children and young people.

Recommendation 1

The Scottish Government and NHS Scotland, building on the *GIRFEC*[2] approach as a platform for integrated service delivery, should further research, pilot and evaluate innovative and flexible multi-disciplinary models for delivering health services to children and young people in the community, ensuring that the individual needs of children and young people are at the centre of decision making, maximising capacity for early identification and timely intervention, with attention given to the interfaces children encounter as they progress through primary, secondary and tertiary care and as they transition to adult care.

Healthcare and public health

Maximising health and wellbeing during pregnancy and infancy

Why children die shows that the majority of deaths during childhood occur during the first year of a child's life. Workstream 1 (conception to one year) of the *Early Years Collaborative (EYC)* is therefore a welcomed commitment by the Scottish Government to reducing stillbirth and infant mortality, focusing on a range of key actions pre and post birth to foster positive pregnancies[4].

Preterm birth and low birthweight are crucial risk factors for premature death during infancy and are risk factors which disproportionally affect the most disadvantaged in society[8]. In 2010, similar to the rest of the UK, 6.5% of live births in Scotland were of a low birthweight (less than 2500 grams) and 7.0% were preterm (less than 36 weeks gestation)[8].

Smoking has been identified as one of the most important modifiable risk factors for adverse pregnancy outcomes, with over 11,000 Scottish babies affected by, and 20 infant deaths directly attributable to, smoking in pregnancy every year[9]. The *Scottish Patient Safety Programme,* maternity care strand, signals a commitment to reducing smoking in pregnancy through targeted interventions including carbon monoxide (CO) monitoring[10]. These interventions, coupled with population measures aimed at reducing the uptake of smoking in young people as set out in *Creating a tobacco-free generation: a tobacco control strategy for Scotland*[11] are required to reduce the impact of tobacco on infant mortality.

Maternal age is also a risk factor for child mortality, with research findings of a persistent effect of young maternal age on risk of death throughout childhood in the UK[12]. The Scottish Parliament 2013 *Inquiry into Teenage pregnancy* identified a range of social and economic factors associated with inequality which contribute to high rates of teenage pregnancy, including deprivation, low self-esteem and risk taking behaviours highlighting a need for coordinated local responses to reducing teenage pregnancy which take account of health inequalities[13]. Additionally, despite embedding relationships, sexual health and parenthood (RSHP) education within the Scottish health and wellbeing curriculum, unlike the rest of the UK and many other European nations, there is no statutory requirement in Scotland for schools to teach sex and relationships education.

Identifying when families require additional support and providing early intervention is crucial for reducing risk of premature death during infancy and early childhood and the Named Person for every child, as part of the *GIRFEC*[2] approach, is an important source of identification and referral for vulnerable families. The additional increases in health visitor numbers and the national roll out of the Family Nurse Partnership (FNP) are also welcomed[14]; however there must be sustained investment in these initiatives and clear pathways available to all mothers to access timely and appropriate support, particularly for younger mothers who cannot access targeted programmes, such as the FNP[13].

Breastfeeding is an important protective factor for infant survival and it is therefore encouraging that all hospitals in Scotland are either accredited or working towards UNCEF Baby Friendly accreditation[15,16]. However, the Scottish Government must continue to promote sustained breast

feeding, building on the 2010/11 HEAT Target, Exclusively Breastfeed[17], and the vision set out in the 2011 *Improving Maternal and Infant Nutrition: a framework for action*, with continued emphasis on ensuring all mothers of more vulnerable babies in neonatal settings are adequately supported with feeding.

In 2010, Sudden Unexplained Death during Infancy accounted for 21 (post-neonatal) infant deaths, including deaths due to Sudden Infant Death Syndrome[18]. Therefore, the Scottish Government, health boards and local authorities, in addition to increasing breastfeeding and reducing smoking, must also ensure that all parents and carers are equipped with the knowledge and skills for safe sleeping.

Recommendation 2

The Scottish Government and NHS Scotland through Workstream 1 of the *Early Years Collaborative*[4] and through the *Scottish Patient Safety Programme*[10] should continue to work towards achieving the aims set out to reduce avoidable harm associated with smoking during pregnancy, while continuing to implement actions set out in *Creating a tobacco-free generation: a tobacco control strategy for Scotland*[11], focusing on local tobacco control plans and implementing measures to reduce smoking uptake in young people.

Recommendation 3

The Scottish Government should introduce a statutory requirement for all schools to deliver comprehensive, evidence based, sex and relationships education.

Recommendation 4

The Scottish Government should carry out an annual audit of measures being taken in areas with high rates of teenage pregnancy to reduce these rates, through monitoring the implementation of existing guidance, *Reducing teenage pregnancy: Guidance and self-assessment tool*[19], as well as mapping the sufficiency of sexual health services and targeted education programmes, holding health boards and local authorities to account for progress.

Recommendation 5

The Scottish Government and NHS Scotland should build on the *Improving Maternal and Infant Nutrition: A Framework for Action*[15] and the 2010/11 HEAT Target, Exclusively Breastfeed[17], to continue to promote breastfeeding in Scotland considering actions such as:

- raising awareness of the benefits of breastfeeding, particularly in areas where there are low rates of breastfeeding
- ensuring that there is adequate infrastructure which supports all women to initiate and maintain breastfeeding
- ensuring neonatal services recruit staff or train existing staff to deliver specialist breastfeeding advice and support

Recommendation 6

The Scottish Government through roll out of the Named Person under the *GIRFEC*[2] approach should ensure that all families who are identified as requiring additional support can access timely and appropriate services, particularly younger mothers at greater risk of difficulties and who cannot access targeted programmes such as the Family Nurse Partnership.

Recommendation 7

The Scottish Government in partnership with NHS Scotland should develop a targeted awareness campaign to promote safe sleeping, raising awareness of the potential risks of co-sleeping and considering the additional needs of more vulnerable families where multiple risk factors may be present, e.g. parental smoking.

Reducing deaths from injuries and poisoning

Why children die highlights how a large proportion of preventable deaths during childhood and adolescence occur in the context of children and young people's interactions with their external environment, with the most common causes of death including transport accidents, drowning and intentional injuries.

While injury mortality rates across the UK are relatively similar for children aged one to nine years there is increasing disparity for children aged 10 to 18 years, and if Scotland were to have the same injury mortality rate (including deaths due to suicide) as England, there would have been 113 fewer deaths of children aged 10 to 18 years between 2006 and 2010[12].

For younger children, injuries and poisonings are among the leading causes of highly preventable death, therefore safety in the home and in the community is of paramount importance. Parents and carers need to be supported to make safety a priority, ensuring they are equipped with knowledge and skills as well as resources for creating safe physical environments.

Road traffic accidents are a major cause of preventable death during childhood and adolescence, and on average six children (under 16 years) died annually on Scotland's roads between 2011 and 2013[20]. On average, between 2009 and 2013, there were two pedestrian fatalities, one pedal cyclist fatality and two car fatalities involving children[21], signalling a need to better protect children through targeted measures, including lowering speed limits and maximising spatial planning to promote the safety of pedestrians and cyclists.

On average, 34 young drivers (aged 17 to 25 years) were killed each year in Scotland between 2005 and 2009, accounting for 34% of all fatal crashes involving car drivers over this time period[22]. Crashes on Scottish roads involving drivers aged 17 to 25 years often include young passengers[23], therefore measures must be taken to ensure the safety of young drivers and their passengers, looking to international best practice for policies which have been shown to reduce fatalities, including graduated licensing schemes[24].

Recommendation 8

Local authorities and health boards should prioritise children's safety, and through utilising resources such as health visitors and home safety equipment schemes, educate and equip parents and carers to keep their children safe, with a focus on water safety, blind cord safety, and safe sleeping.

Recommendation 9

The Scottish Government should reduce speed limits in build-up areas to 20mph.

Recommendation 10

The Scottish Government should pursue mechanisms for the introduction of a Graduated Licensing Scheme for novice drivers.

Recommendation 11

Local authorities should ensure that Directors of Public Health oversee and sign off transport and spatial plans to confirm that they will promote the safety and wellbeing of children.

Promoting mental health and reducing risk-taking behaviours

Why children die shows adolescence to be the second riskiest time for death under 19 years of age in the UK, with many of these deaths a result of suicide, self-harm or assault.

Between 2009 and 2012 there were 87 probable male suicides and 44 probable females suicides in children and young people aged between 5 and 19 years in Scotland; an annual rate of 5 per 100,000 and 3 per 100,000 respectively[25]. Suicide data for both adults and children in Scotland shows a strong deprivation effect, with the suicide rate more than three times higher in the most deprived fifth of the population than in the least deprived fifth[26].

The Scottish *Children and young people's Mental Health Indicators*[27] set is an important tool enabling government and policy makers to monitor the mental health and wellbeing of children and young people. An analysis of this data over the past decade has shown that although the mental health of children and young people has improved over time, there are still substantial opportunities for improvement[28].

Specifically, the indicator set shows how mental wellbeing generally deteriorates with age, highlighting a need for increased in effort in supporting children as they transition through adolescence and into young adulthood[28], through educating professionals on the early signs and symptoms of mental health difficulties, promoting positive behaviours in children and young people, and ensuring mental health issues are followed-up in a timely way.

There must also be a continued focused on and adequate service provision for children and young people who are known to be at a greater risk of mental health difficulties, including looked after children, children involved in youth justice, children who have been excluded from school and children with a history of self-harm.

Misuse of alcohol and drugs has been identified as a significant modifiable risk factor in the prevention of suicide[29]. In Scotland while the overall number of children and young people drinking alcohol has decreased, the number of units being drunk has increased[28], suggesting that children and young people who consume alcohol are consuming it in larger, and potentially more risky, quantities. The introduction of a minimum unit price on alcohol through the *Alcohol (Minimum Pricing) (Scotland) Act 2012*[30] shows a clear commitment to reducing harm associated with misuse of alcohol, and should be coupled with strategies to further restrict access to alcohol by young people.

Recommendation 12

The Scottish Government should ensure that compulsory evidence based health and wellbeing programmes are embedded in all primary and secondary schools which foster social and emotional health and wellbeing, through building resilience, and specifically tackling issues around social inclusion, bullying, drug and alcohol use, and mental health.

Recommendation 13

The Scottish Government should continue to pursue mechanisms to further restrict the access of children and young people to alcohol, including regulation of marketing and availability, and action on under-age sales.

Recommendation 14

Early identification of mental health difficulties should be established as a core capacity of all health, social care and education professionals who work with children and young people through the promotion and evaluation of educational resources such as the *MindEd e-portal*[31] across the children's workforce.

Recommendation 15

The Scottish Government should continue implementation of the *Mental Health Strategy for Scotland: 2012-2015*[32] ensuring timely access to services across all tiers of service, particularly for those most at risk of suicide and other risk taking behaviours, including looked after children, children involved in youth justice, children who have been excluded from school, and children with a history of self-harm.

Reducing healthcare amenable deaths

The importance of high-quality healthcare for children in the community and in acute settings is also highlighted in *Why children die*. Children, young people and their families must be confident that health issues will be identified early, that they will receive the safest possible care, and that they are supported appropriately in the community to manage any ongoing conditions.

The *Scottish Patient Safety Programme*[10]*,* paediatric and neonatal care strands, provides a strong platform for identifying, recording and reducing avoidable harm in acute paediatric settings, and findings from this initiative should be widely disseminated to enable service improvement. Additionally, the implementation of the Scottish *Child Death Review System*[5] should provide further evidence about risk factors and actions which can be taken to reduce risk of childhood mortality.

Health plans have been identified as important tools for managing medical conditions, with asthma and epilepsy being two examples of this. The National Review of Asthma Deaths recommended that all people with asthma have a personal asthma action plan, and that parents and children, and those who care for or teach them, should be educated about managing asthma[33]. Additionally, a recent review of healthcare received in cases of mortality and prolonged seizures in children and young people with epilepsies highlighted the importance of comprehensive management plans to ensure coordinated care between parents, schools and other carers to enable timely and appropriate responses to acute episodes of ill health[34].

It is vitally important that educational settings are well equipped to manage children and young people with medical conditions. In 2013, Scotland's Commissioner for Children and Young People (SCCYP) published research looking at the administration of medicines and healthcare procedures in schools for children and young people with long term health conditions[35]. The report highlighted a need to improve consistency of practice across local authorities, through updating the existing guidance, *The Administration of Medicines in Schools*[36]*,* and also addressing the voluntary nature of administering medicines by members of school staff as there is currently no legal duty requiring staff in education to administer medicines or healthcare procedures. The SCCYP has also highlighted a need for staff within schools to be well equipped with the knowledge and skills in order to provide safe and effective care through appropriate training.

Recommendation 16

NHS Scotland and relevant professional associations should ensure all frontline health professionals involved in the acute assessment of infants, children and young people utilise resources such as the *Spotting the sick child* web resource[37] and complete relevant professional development so they are confident and competent to recognise a sick child.

Recommendation 17

NHS Scotland and local health boards should ensure that clinical teams looking after children and young people with known medical conditions make maximum use of tools to support improved communication and clarity around ongoing management, utilising specific resources within healthcare planning such as epilepsy passports or asthma management plans where appropriate.

Recommendation 18

In line with recommendations from the SCCYP, the Scottish Government should continue developing guidance on the administration of medicines and healthcare procedures in schools, focusing not only on medicine administration, but all elements of care required, ensuring that the individual needs and rights of each child are considered and that the guidance addresses the voluntary nature of administering medicines by members of school staff; including the provision of comprehensive staff training.

Recommendation 19

NHS Scotland, through Health Improvement Scotland's *Scottish Patient Safety Programme*[10], along with local health boards should ensure all adverse events in hospitals which may have contributed to the premature death of an infant, child or young person are reviewed and the findings widely disseminated to enable clear recommendations and guidance to be developed to enable service improvement.

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