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

May 2014

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

ROYAL COLLEGE OF PAEDIATRICS AND CHILD HEALTH NATIONAL CHILDREN'S BUREAU





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

A policy response for England to the report *Why children die: death in infants, children and young people in the UK - Part A* 

Royal College of Paediatrics and Child Health National Children's Bureau

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## Foreword

In 2012, more than 5,300 children between 0 and 19 years died in the UK. Although the child mortality rate has declined in recent years, it is far higher than in other, similar European countries. Around six out of ten of these deaths occur in infancy - over 3,000 babies died before their first birthday - and one in five between the ages of 15 and 19. The shocking truth is that many of these deaths are preventable.

Poverty, inequality, and where a family lives are risk factors for death in childhood, from infancy through to young adulthood and beyond. That means not only do we need to identify interventions that directly reduce risk, we also need to consider what action government takes to reduce risk through tackling child poverty and social inequality. Social policy and fiscal policy matter to children's chances of survival.

Giving children and families the tools they need is also critical. We should prioritise prevention and equip children and young people with the knowledge and skills that enable them to better protect their own – and parents their children's – health. That principle should underpin a range of activities from promoting breastfeeding, to recognising and responding to early signs of social and emotional difficulties, to encouraging informed decision-making about early sexual activity or drinking.

Our recommendations focus on strengthening the public health response to children and young people, and their parents and carers: accessible information to help parents give their children the best start in life; advice for children and families on how to stay safe and avoid accidents in their homes and the community; education to help children and young people understand their health needs and develop resilience; and public awareness campaigns to promote healthy lifestyles. They also set out how health services need to be improved, particularly mental health provision for children and young people. More importantly a coordinated response involving the health, social care, and education sectors is required.

Crucially, our recommendations require central and local government to act to reduce child deaths. We can and should be doing better. If we were doing as well as those countries with the lowest child death rates, 1,951 lives would be saved every year – that's around five fewer deaths each day.

Government has been joined by key agencies in the health system in signing up to *Better health outcomes for children and young people: our pledge*<sup>1</sup>. The Secretary of State for Health has also stressed that he wants to see positive progress in reduction of inequalities in infant mortality, and NHS England have set out a number of important actions in their business plan for 2014-15<sup>2</sup>. Such steps indicate a welcome increase in focus on the importance of ensuring all children get the best start in life.

But to be the best in the world, we need to have far higher aspirations for what we can achieve as a nation for our children. At present we have a set of piecemeal policies that lack coherence for every child to thrive and do well. A more joined up vision and strategy is required from all political leaders, followed through with action and real improvements in children's lives.

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Dr Hilary Cass, President, RCPCH

Dr Hilary Emery, CEO, National Children's Bureau

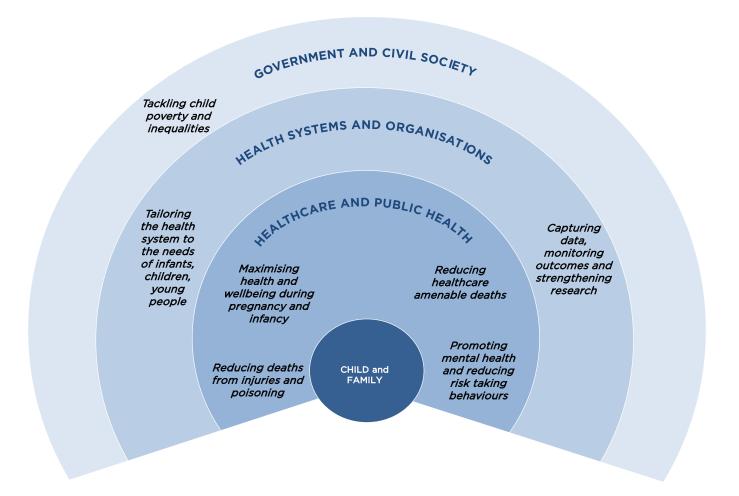
# Introduction

Why children die: death in infants, children and young people in the UK - Part A (Why children die) highlights the complexity of issues which surround mortality during childhood and demonstrates how a child's chance of survival is impacted not only by the health services they receive but by socioeconomic conditions which may predispose them to negative health outcomes.

The policy recommendations set out in this paper therefore take a comprehensive approach to tackling the causal risk factors for premature death, expanding on the key themes of *Why children die* with the aim of maximising conditions for children to survive and thrive.

As illustrated below the recommendations cut across the key domains outlined in the report: government and civil society; health systems and organisations; healthcare and public health.

This paper outlines recommendations for reform in England and the vital contribution that should be made by central and local government, NHS England, Public Health England and Health Education England in taking important steps to dramatically reduce the number of child deaths.



# **Government and civil society**

## Tackling child poverty and inequalities

One of the strongest themes emerging from *Why children die* is the impact of poverty and social inequality on child mortality and children's life chances, illustrated by the fact that mortality rates are noticeably higher for babies born into low income households compared to those born into wealthier households.

One in four children are living in poverty in the UK – in total 3.5 million children<sup>3</sup> - and the number is set to rise in the future. By the next election it is estimated that more than four million children will be living in poverty<sup>4</sup>. Poverty and inequality matters to child health and to the number of child deaths each year.

#### **Recommendation 1**

The Independent Office for Budget Responsibility should disclose the impact each budget would have on child poverty and inequality in the report it publishes alongside the Chancellor's annual statement.

#### **Recommendation 2**

The government's next Child Poverty Strategy should focus in more detail on health inequalities and should be supported and sponsored by the Department of Health as well as the Department for Education, Department for Work and Pensions, and Treasury. It should also be informed by and directly link to the work of Public Health England.

#### **Recommendation 3**

The Child Poverty Strategy should also set out a detailed step by step plan for how central and local government will meet the national target to eradicate child poverty by 2020.

#### **Recommendation 4**

The new cap on welfare spending should be withdrawn and the government should ensure that a sufficient social safety net is in place so that the risks of rising living costs – such as higher child care and rent costs – are not transferred from the Treasury to families on low incomes who are struggling to provide for their children.

# Health systems and organisations

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

Why children die highlights an imperative for health systems to adapt to the evolving needs of infants, children and young people and to be configured in a way which optimises paediatric health and safety.

Primary care services must be equipped to identify children with early signs of illness, enabling them to be adequately assessed and managed at point of first contact<sup>5</sup>, ensuring all children receive the right care at the right time before concerns have an opportunity to escalate.

Given the high number of deaths during the neonatal period, there is also an imperative to review models of care for these particularly vulnerable infants, to identify opportunities where care could be improved with the aim of reducing overall mortality. The NHS Business Plan for 2014-15<sup>2</sup> outlines a plan to undertake 30 national clinical audits, including a Maternity and Perinatal National Clinical Audit. This commitment to improving maternity and perinatal outcomes is welcomed.

In addition to better understanding and identifying areas for improvement within the NHS, further insight and comparison with better performing European nations, such as Sweden, is also needed to maximise the impact of any changes to the health system on the lives of children and young people.

#### **Recommendation 5**

The Department of Health should commission an analysis of health system models to identify opportunities for improvement in how care is initiated, delivered and coordinated for infants, children and young people. This should include:

- examination of interfaces that infants, children and young people make as they progress through primary, secondary and tertiary services and as they transition to adult services
- close examination of UK neonatal care settings, their alignment with international standards, and opportunities for flexible, multi-disciplinary approaches to reduce mortality
- examination of the prevention and better management of non-communicable diseases, such as asthma and epilepsy
- consideration of the significance of differences between the UK health system and better performing European neighbours.

#### **Recommendation 6**

NHS England should develop, pilot and evaluate innovative and flexible multi-disciplinary models for delivering health services to children and young people in the community, with findings of pilots encompassed within best practice recommendations for NHS England and local health authorities.

The Children and Young People's Health Outcomes Forum report of 2012<sup>6</sup> made a wide range of recommendations for how the health system could deliver better outcomes for children and young people. Many of these will have particular relevance for efforts to reduce avoidable deaths, through improved training, coordination of care and ensuring accountability and incentive mechanisms do not undermine investments in children's health care.

Responses to these recommendations are at varying degrees of development and implementation, and as the Forum's most recent annual report sets out progress needs to be accelerated.

#### **Recommendation 7**

Progress should be accelerated on implementing all the recommendations of the Children and Young People's Health Outcomes Forum, particularly around prevention, safe and sustainable services and the education and training of the workforce. The Department of Health should publish an annual report setting out progress on meeting the Forum's recommendations.

### Capturing data, monitoring outcomes and strengthening research

*Why children die* provides a broad overview of the causes of death in childhood, however, it also highlights the need for further research to better identify risks and protective factors for survival during infancy and childhood, as well as interventions to tackle these.

Integral to this investigation is the availability of comprehensive child mortality data. In 2013, a report<sup>7</sup> published by the Department for Education outlined several areas where the collection and dissemination of child mortality data through the Child Death Overview Panel process could be improved, specifically recommending a national database for child mortality data to be developed. Given the relatively small number of child deaths, however, it is also imperative that child death data from England can be analysed alongside comparable data from across the four nations to monitor patterns and trends throughout the UK.

#### **Recommendation 8**

The Department for Education and Department of Health should establish a national database for the collection, analysis, interpretation and reporting of child mortality data at a national level, and work with partners in Wales, Northern Ireland and Scotland to ensure mortality data can be compared and analysed across the four nations.

To complement mortality data, there is also a need to more rigorously monitor child health outcomes across the UK. The Children and Young People's Benchmarking Tool<sup>8</sup>, developed by the Child and Maternal Health Intelligence Network and in response to the recommendations of the Children and Young People's Health Outcomes Forum, is a welcome step for improving child and adolescent health monitoring. The tool brings together and builds upon health outcome data from the Public Health Outcomes Framework and the NHS Outcomes Framework.

There remains, however, a need to strengthen the capacity for data to be compared internationally, offering greater insight into why variation in child mortality across comparable countries exists. The Euro-Peristat project is an example of international data comparison in which European data

on infant mortality, low birthweight and preterm birth is presented alongside data on health care and maternal characteristics that can affect the outcome of pregnancy<sup>9</sup>.

The International Cancer Benchmarking Partnership (ICBP) is a further example. The ICBP was established in 2009 to seek to understand how and why cancer survival varies between the UK and other comparable countries and jurisdictions. By benchmarking cancer diagnosis, treatment and outcome data, researchers are able build a picture of where improvements in practice can be made<sup>10</sup>.

A similar partnership for child mortality would be welcomed, enabling a clearer understanding of why the UK has poorer child mortality outcomes compared with some other European neighbours.

#### **Recommendation 9**

Public Health England should continue to develop the Children and Young People's Health Benchmarking tool into a comprehensive suite of indictors of child health outcomes and look to include measures that can aid international benchmarking.

Finally, it must be acknowledged that investment in child and adolescent health research is an investment in the future health of our entire population<sup>11</sup>. Key research stakeholders must work together to facilitate greater understanding of what leads to, and what prevents, premature death in infancy, childhood and adolescence.

#### **Recommendation 10**

All research authorities, foundations and universities should support multidisciplinary crossinstitutional clinical and non-clinical child health research to strengthen the evidence-base for child mortality, with a particular focus on better understanding the causes of prematurity and low birth weight.

# Healthcare and public health

## Maximising health and wellbeing during pregnancy and infancy

*Why children die* highlights how over half of deaths in childhood occur during the first year of a child's life. These deaths are strongly influenced by preterm delivery and low birthweight; risk factors which disproportionately and alarmingly affect those most disadvantaged in our society<sup>9</sup>.

Smoking during pregnancy is recognised as one of the most important preventable factors associated with adverse pregnancy outcomes. Smoking has been found to impair normal foetal growth and development and as a result increase the risk of low birth weight, preterm birth, intrauterine growth restriction, and some congenital abnormalities<sup>9</sup> as well being linked to an increased risk of stillbirth<sup>13</sup>. Smoking has been attributed to around 2,200 preterm births, 5,000 miscarriages and 300 perinatal deaths every year in the UK<sup>12</sup>.

Despite being an established risk factor for infant mortality, the UK continues to have high rates of smoking in pregnancy; with infants from deprived backgrounds more likely to be born to mothers who smoke, and to have much greater exposure to second-hand smoke in childhood<sup>14</sup>. The National Institute for Health and Care Excellence (NICE) have developed clear guidance on quitting smoking in pregnancy and following childbirth<sup>15</sup>, however, implementation is patchy<sup>16</sup>.

Action on Smoking and Health (ASH), in collaboration with partners, have developed key recommendations<sup>17</sup> to ensure NICE guidance is implemented, with specific recommendations related to audit and implementation; identifying and referring smokers; and the provision of local stop smoking services, with a particular imperative for carbon monoxide (CO) screening to be incorporated into routine pregnancy care. CO screening is an immediate and non-invasive biochemical method for helping to assess whether or not someone smokes.<sup>15</sup> NICE recommends that midwives undertake CO screening at a woman's first antenatal appointment to identify if they could benefit from a referral to a stop smoking service. CO screening is also used to identify exposure to second-hand smoke and other sources of CO (such as through faulty gas appliances)<sup>15</sup>.

Additionally, the National Institute for Health Research<sup>18</sup> is funding research to gain a better understanding of the barriers and facilitators to smoking cessation in pregnancy and following childbirth, the findings of which should be reflected in future policy and initiatives.

As well as targeted approaches for smoking cessation during pregnancy, population measures are also vital in reducing the number of young people taking up smoking. We therefore welcome the government's recent announcement<sup>19</sup> that they intend to draft regulations for standardised cigarette packaging in the United Kingdom. This was in response to the compelling case made by Sir Cyril Chantler's independent review<sup>20</sup>, which found that standardised packaging is very likely to lead to an important reduction over time on the uptake and prevalence of smoking in the population.

#### **Recommendation 11**

The Department of Health, NHS England Public Health England, Health Education England and the Royal Colleges should progress implementation of the recommendations outlined in 'Smoking cessation in pregnancy: A call to action'<sup>17</sup> with particular focus on implementation of carbon monoxide screening in to routine pregnancy care.

From 2015 Public Health England and local authorities should set out and monitor new national and local targets for reducing smoking rates across all stages of pregnancy and early parenthood.

#### **Recommendation 13**

All local authorities' service specifications for smoking cessation should set out how these services will be tailored to meet the needs of pregnant women in line with NICE guidance. Public Health England should publish standard specifications to support this process.

Maternal age is also a significant risk factor for infant and child mortality, with both early and late childbearing associated with higher than average rates of preterm birth, growth restriction, perinatal mortality, and congenital abnormalities<sup>9</sup>.

The 2013 Child Health Review-UK (CHR-UK) overview of child deaths<sup>21</sup> found a persisting effect of young maternal age on risk of death throughout childhood. CHR-UK identified that children born to mothers less than 30 years of age were at an increased risk of death compared to mothers aged 30-34 years; this association was independent of birth weight but closely linked to social disadvantage<sup>21</sup>.

The percentage of women giving birth aged 35 years or over in the UK, is similar to better performing nations like Sweden; 20% compared with 22%<sup>9</sup>. However, compared with a European average 2.7%, the UK has a higher rate of teenage births, with over 5% of births to women younger than 20 years<sup>9</sup>. While the under 18 conception rate continues to gradually fall in England<sup>22</sup>, there is great regional variation and an imperative to systematically tackle this risk factor.

#### **Recommendation 14**

The Department for Education should ensure that all schools make provision for high quality sex and relationships education, and that through this and wider Personal, Social, Health and Economic education (PSHE) programmes, young people are taught the basics about the importance of healthy behaviours during pregnancy.

#### **Recommendation 15**

Public Health England should carry out an annual audit of measures being taken in areas with high rates of teenage pregnancy to reduce these rates, mapping the sufficiency of sexual health services and targeted education programmes, and holding local authorities to account for progress.

Breastfeeding has also been shown to be an important protective factor for perinatal and infant survival<sup>9,23</sup>. Despite this, breastfeeding rates in the UK remain low in comparison to other parts of Europe, with mothers and babies with the worst health outcomes most likely to come from

population groups least likely to breastfeed, including young mothers and mothers from lower socioeconomic groups<sup>24</sup>.

There is an imperative for government, health agencies and health services to ensure women understand the importance of breastfeeding, that they feel socially supported to breastfeed, and that they are able to access appropriate breastfeeding resources.

The UNICEF UK Baby Friendly Initiative is a best practice framework for health services which ensures support is provided to parents to make informed decisions about feeding their babies. Facilities and institutions that meet the required standards can be assessed and accredited as Baby Friendly. Research has shown that mothers giving birth in hospitals where baby friendly policies are implemented are more likely to breastfeed than mothers who give birth in other hospitals<sup>25,26</sup>.

For infants born preterm, breast milk has been shown to be of considerable additional benefit; associated with a reduction in potentially life-threatening conditions such as infection and inflammation of the bowel tissue known as necrotising enterocolitis (where tissues in the intestine become inflamed and start to die)<sup>27</sup>. Mothers of preterm infants, however, may require additional assistance for breastfeeding; therefore additional support for these women should be prioritised in neonatal units.

#### **Recommendation 16**

NHS England should encourage and support Clinical Commissioning Groups and providers to ensure that all maternity services obtain UNICEF UK Baby Friendly Initiative accreditation by 2016.

#### **Recommendation 17**

Public Health England should work with government departments, NHS England and representatives of local government to develop a national strategy for the promotion of breastfeeding. This should be wide ranging and evidence based with progress evaluated annually. In addition to continued support from health visiting and other key services, it should consider actions such as:

- awareness raising of the benefits of breastfeeding
- highlighting the importance of infrastructure which supports women to breastfeed
- ensuring neonatal services recruit staff or train existing staff to deliver high quality breastfeeding advice.

Why children die also demonstrates the negative impact of disadvantage and vulnerability on a child's chances of survival, highlighting the importance of mechanisms which support families during pregnancy, infancy and early childhood.

Targeted early intervention programmes, such as the Family Nurse Partnership (FNP), offer first time parents under 20 years of age intensive, structured, home visiting by specialist nurses<sup>28</sup>.

Research from the United States has provided a strong evidence base for this approach to improving maternal behaviours<sup>29</sup> and the programme is currently being evaluated in England through a large-scale randomised controlled trial due to report initially in 2014<sup>30</sup>.

The universal Health Visiting Service<sup>31</sup> (HVS) is also an important resource for families, providing health assessments and interventions during the first 2.5 years of life. The HVS is well placed to ensure all families have access to the knowledge, skills and resources which promote health and safety, including breastfeeding advice, and information around safe sleeping. The HVS is also well placed to identify early signs of parental mental illness and difficulties within a family such as substance misuse and domestic violence, thus referring appropriately.

While current expansions to both of the FNP and HVS are welcomed, governments and local authorities must also ensure that these programmes receive sustained investment, and are linked to primary care strategies which take proper account of the needs of young children and their families as well as ensuring they reach all those who need this support. Local authorities should build on their offer to pregnant women and families in line with a progressive universalism approach.

#### **Recommendation 18**

From 2015 when local authorities take over public health provision for 0 to 5 year olds they should prioritise and sustain investment in both universal and targeted maternal and child health services. This should include:

- offering intensive support via the Family Nurse Partnership to all first time mothers under 20 years of age
- securing high quality health visiting services for all families of young children, that are well connected and equipped to respond to the needs of more vulnerable families as they arise

*Why children die* also highlights the contribution of Sudden Infant Death Syndrome (SIDS) to the burden of mortality during childhood, therefore there is a need to continue to raise awareness of SIDS, ensuring all families access safe sleeping guidance and resources, in addition to reducing smoking rates in pregnancy.

#### **Recommendation 19**

Public Health England in partnership with local authorities should develop a targeted awareness campaign for vulnerable families to promote safe sleeping habits.

NHS England recently released guidance<sup>32</sup> in partnership with Public Health England to help commissioners reduce premature death through commissioning of neonatal paediatric interventions. These interventions are focused on seven key areas: community based genetic counselling; management of foetal growth retardation; smoking cessation in pregnancy; advice on maternal obesity; maternal and perinatal mental health; and maternal mental health. This guidance must be recognised and acted upon.

NHS England should set out annually how it is working with Clinical Commissioning Groups to ensure the principles in 'Our Ambition to Reduce Premature Mortality: a resource to support commissioners in setting a level of ambition'<sup>32</sup> are being followed in the commissioning of all relevant health services.

## Reducing deaths from injuries and poisoning

Why children die shows 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 environments.

It is paramount that children, young people and their families have adequate knowledge and skills to minimise hazards at home and in the community, through the provision of information and safety resources which align appropriately with developmental stages.

As highlighted in the Annual Report of the Chief Medical Officer (CMO) 2012<sup>33</sup>, there is also an emerging concern related to the number childhood deaths attributable to blind cord strangulation. The CMO has recommended that the Chief Medical Officer in Northern Ireland lead a UK-wide group with the four public health agencies and The Royal Society for the Prevention of Accidents (RoSPA) to develop strategies to combat blind cord deaths; a recommendation which is reflected in this response.

#### **Recommendation 21**

Local authorities should make maximum use of children's centres, health visiting services and safety equipment schemes to educate and equip parents to keep their children safe; with a focus on water safety, safe sleeping and blind cord injury prevention.

#### **Recommendation 22**

Public Health England should ensure that the investigation into the prevention of blind cord deaths, as recommended by the Chief Medical Officer for England, be carried out and subsequent recommendations be implemented.

In 2012, there were 116 road-related deaths of children aged between 0 and 17 years<sup>34</sup> and there are a number of policy levers which could be implemented to improve the safety of young drivers and passengers which would align UK policy and legislation with international best practice. This would include the introduction of a Graduated Licensing Scheme for novice drivers which has been shown to reduce road related deaths in countries including the United States, Canada, New Zealand and Australia<sup>35,36,37,38</sup>. Research undertaken in London has also shown that the introduction of 20 mph zones was associated with a 42% reduction in road casualties<sup>39</sup>.

Additionally, the ability of children and young people to negotiate their surroundings safely should take priority in the way we design our communities. Local authorities should be encouraged to examine the safety of the built environment while acknowledging the importance of promoting physical activity during childhood and adolescence.

The national speed limit in built-up areas should be reduced to 20mph.

#### **Recommendation 24**

Graduated Licensing Schemes should be introduced for novice drivers of all ages.

#### **Recommendation 25**

Directors of public health should sign off local 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 late adolescence as the second riskiest time for death under the age of 19 years, with a large proportion of the mortality burden in adolescence is related to intentional injuries linked to poor mental health and wellbeing, including self-harm, suicide, drug abuse and assault.

Throughout Europe, interpersonal violence is the third leading cause of death among people aged between 10 and 29 years<sup>40</sup>. Building resilience, promoting respect and fostering positive social interactions is vital for reducing these deaths. Families, communities, and importantly schools must recognise the role they can play in promoting positive social interactions and reducing risk-taking behaviours in children and young people.

The NICE local government briefing, *Social and emotional wellbeing for children and young people*, recommends the adoption of comprehensive organisation-wide approaches for promoting social and emotional wellbeing in educational settings<sup>41</sup>. Schools must be supported to adopt these approaches and be held to account if they fail to do so.

Furthermore, the role of Personal, Social, Health and Economic education (PSHE) must be examined and strengthened in relation to social and emotional health and wellbeing, ensuring all children and young people are equipped with the knowledge, skills and support to make positive life choices.

#### **Recommendation 26**

Ofsted's inspection framework for early years settings, schools and colleges should include consideration of the extent to which these settings provide an environment that promotes children and young people's social and emotional wellbeing and this should be a 'limiting judgement'. An equivalent approach will need to be taken for all settings in which children and young people may find themselves, such as children's homes and youth justice settings.

The Department for Education should ensure that high quality, comprehensive personal, social and health education (PSHE) programmes are implemented across 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.

Suicide remains a leading cause of death in young people in the UK<sup>33</sup> and while there is no single reason why a child or young person takes their own life, there are a number of risk factors which can be systematically tackled including deprivation; alcohol and substance misuse; physical, emotional and sexual abuse; self-harm; and social connections<sup>41</sup>.

A recent thematic review of deaths of children and young people through probable suicide in Wales<sup>42</sup> highlighted misuse of drugs and alcohol as a significant modifiable risk factor in the prevention of suicide, recommending that more be done to restrict access to alcohol by children and young people; a recommendation which is mirrored in this response.

#### **Recommendation 28**

Government should take further steps to restrict access to alcohol by children and young people, including the introduction of a minimum price per unit, regulation of marketing and availability, and action on under-age sales.

Approximately three quarters of lifetime mental health disorders (excluding dementia) have their onset before 24 years of age. The peak onset of most conditions is between 8 and 15 years<sup>43</sup>, with children and young people in the poorest households three times more likely to have a mental health problem than their wealthier counterparts<sup>44</sup>.

It is widely acknowledged that mental health outcomes for children and young people can be significantly improved through early identification, timely assessment and treatment<sup>45</sup>. Family, friends and peers as well as health and education professionals have a pivotal role in recognising early signs of mental health difficulties and helping children and young people access the services they need. Therefore, the importance of mental health must be embedded within communities and institutions.

#### **Recommendation 29**

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, including the ability to secure further support for the child when it is needed. The Department of Health should continue to work with delivery partners to develop and disseminate the MindEd e-portal, maximising its use across the children's workforce.

The unequal distribution of mental illness amongst the UK's most vulnerable children and young people clearly demonstrates that more must be done to ensure children at high risk receive targeted mental health support.

Recent cuts to Child and Adolescent Mental Health Services (CAMHS) funding across the UK have raised significant concerns that it could lead to a greater reduction in the ability for children and young people to access the evidence-based treatments they need<sup>46</sup>, adding further to the burden of illness associated with mental ill health in children and young people. High quality, local data must be collected which underpins decision making and supports adequate investment in CAMHS to reflect current need.

#### **Recommendation 30**

Reflecting the recommendations of the Chief Medical Officer for England (CMO), a regular survey should be commissioned by the Department of Health to identify the prevalence of mental health problems among children and young people. NHS England should ensure through its assurance and direct commissioning roles that this forms the basis of commissioning of CAMHS services across the country. This can be assessed through the annual audit of services and expenditure recommended by the CMO.

#### **Recommendation 31**

The Department of Health should set out an action plan for improving child and adolescent mental health services encompassing all levels of provision (Tier 1 to Tier 4) with a clear focus on prevention and early intervention, backed by additional resource, to ensure there is parity of esteem for children and young people, particularly for those most at risk of mental health difficulties (e.g. looked-after children, children involved in youth justice, and children who have been excluded from school).

## Reducing healthcare amenable deaths

*Why children die* illustrates the importance of access to high quality paediatric health care, whether in the community or acute care settings.

On entering the health system, children, young people and their families must be confident that any issues will be picked up early. As such, all healthcare professionals who come into contact with children and young people must be trained to be confident and competent to recognise a sick child, thus enabling early identification and treatment.

Where further medical intervention is needed, children and young people must be confident that the care they receive is as safe as possible, without risk of an adverse event occurring, such as a medication error or preventable infection. Therefore healthcare services must continuously strive to maximise patient safety.

Additionally, children with long-term or pre-existing medical conditions must have access to high quality ongoing management. A recent review of healthcare received in cases of mortality and prolonged seizures in children and young people with epilepsies<sup>47</sup>, clearly 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 illness. Improvements are needed to ensure that all children and young people with pre-existing medical conditions, such as epilepsy or asthma, and their schools and carers are confident and competent to safely manage their condition.

#### **Recommendation 32**

Health Education England and relevant professional associations should ensure all frontline health professionals involved in the acute assessment of children and young people utilise resources such as the 'Spotting the sick child' web resource<sup>48</sup> and complete relevant professional development so they are confident and competent to recognise a sick child.

#### **Recommendation 33**

The Department of Health, guided by NHS England's Children and Young People's Patient Safety Expert Group, should commission an audit of adverse events in clinical settings to identify which of these adverse events are most likely to lead to a child dying prematurely and set out recommendations for clinical practice and service improvements.

#### **Recommendation 34**

NHS England 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, for example:

- introduction of epilepsy passports or asthma management plans where appropriate;
- cooperating with schools to meet their duty to support pupils with medical conditions<sup>49</sup>.

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