Child Health, Health Services and Systems in UK and other European countries

Ingrid Wolfe

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PREFACE

I am a paediatrician and a public health doctor, and these two strands of my work came together and were enriched by developing an interest in children’s health services, systems, and policy research in the UK and Europe. My curiosity about these subjects led to work with Professor Martin McKee on European public health, Professor Staffan Janson on children’s health, and Dr Hilary Cass on UK child health and policy. The work we did together resulted in the publication of research papers and policy reports about children’s health and health services. Invitations to give lectures and speeches followed, as did interviews with media, and meetings with politicians. I began to see that by dedicating my efforts to science and advocacy, I might become a useful bridge between the technical and the political, and thereby hopefully contribute towards improving child health.

I am very fortunate now to be employed by Evelina London Children’s Hospital who created a post in paediatric public health, a new and special professional category, and by King’s College London who are supporting me to develop a children’s population health and policy research team. It is a privilege to be in a position where I can put into practice the things I have researched and written about. I am leading work to design, implement, and evaluate a new type of child health service model. This work is intended to be widely generalisable in order to help meet evolving child health needs and service pressures across the UK and the rest of Europe. My intention is to build and use expertise in child and adolescent population health, services, systems and policy research as a means to improve local and international child health.
The Lancet's decade for child health began in 2000, just as Ellen Key's century of the child ended (1, 2). A remarkable transformation in the lives of Europe's children happened during the 20th century. At the beginning of the century, poor children lived, worked, and fuelled the Industrial Revolution with their labours while scant attention was paid to their lives, health or happiness. By the end of the century, children became widely accepted as people with rights, entitled to education and healthcare.

Child health progress during the 19th and much of the 20th centuries was driven largely by social reform, growing economic security, and public health legislation. More recently, significant advances in medicine and technology have meant that the marginal contribution of healthcare to health has become proportionately more significant. While a growing appreciation for the rights of the child contributed to the improvements in children's life circumstances, by contrast little attention has been devoted to the rights of the sick child.

Children's health systems and services in many countries were designed and are evolving largely around the needs of adults with insufficient regard for the particular concerns of children's lives, health, and wellbeing. Similarly, health systems research has focused largely on adult health, without sufficiently considering child health; and on low and middle-income countries while problems in European health systems have been insufficiently researched. The consequences of weaknesses in European children's health services and systems include avoidable suffering and death. These are remediable problems. Health services and systems for children must be shaped according to evidence, and research is necessary to generate evidence to provoke changes in policy and practice.
Children have the right to the highest attainable standard of health. In European countries, taking forward The Lancet's decade on child health and fulfilling our obligations in the United Nations Convention on the Rights of the Child means strengthening child health services and systems to ensure they make the maximal contribution possible to improving the health of Europe’s children.

This doctorate is dedicated to the work that remains to be done to secure optimal health and welfare for children.
ABSTRACT

Background
This work in child population medicine describes child health problems, assesses health services, systems, and wider determinants, and makes recommendations for improvements.

Aims
To explore trends in UK child health and health service quality and highlight policy lessons from the UK and other European countries.

To study child health and health services in western Europe and derive lessons from different approaches to common challenges.

To enhance knowledge on child to adult transition care.

To describe trends in UK and EU15+ child and adolescent mortality and seek explanations for deteriorating UK health system performance, and make recommendations for improving survival.

Methods
Population level measures of health status and system performance; primary and secondary research on policies and practice for health system assessments. Quantitative: mortality rate trends, excess deaths, DALYs, healthcare processes Qualitative: case reports, system descriptions, analyses.

Results
European child survival has improved, but variably between countries. The UK has not matched recent EU mortality gains. There are 6,000 excess deaths annually in children under 15 years in EU15 countries.

There are child survival inequities; countries investing in social protection have lower mortality. Children in the UK, compared with other EU countries, are more likely to be poor than adults.

Non-communicable diseases are now dominant causes of child death, disease, and disability.

Mortality, processes and outcomes of healthcare amenable conditions vary between countries. Better outcomes seem to be associated with flexible health care models promoting cooperation, team working, and transition.

Conclusions
Child health in Europe is improving, but unevenly. Child health systems are not adapting sufficiently to meet needs. Recommendations are made for improving health systems and services.

Key words: child health, public health, health services and systems assessment, UK, Europe
SAMMANFATTNING

Bakgrund
Denna avhandling inom ämnet folkhälsovetenskap beskriver barns hälsoproblem i Europa och hur man genom ökad kunskap om hälsoservice, hälsosystem och andra övergripande påverkansfaktorer kan ge rekommendationer till förbättringar.

Avhandlingens målsättningar
2. Att studera barns hälsa och hälsoservice i Västeuropa och dra lärdomar från hur man med olika angreppssätt hanterar likartade problem.
3. Att öka kunskapen om vård i övergången mellan barn och vuxenliv.
4. Att beskriva trender i England och EU15+ rörande dödsfall hos barn- och ungdomar, försöka förklara det försämrade utfallet för det engelska hälsosystemet samt ge rekommendationer för att förbättra engelska barns överlevnad.

Metod

Resultat

Slutsatser
Barns hälsa och överlevnad i Europa förbättras, dock mer i vissa länder än i andra. Hälsoystemen har inte anpassats tillräckligt för att möta barns hälsobehov och rekommendationer ges för att stärka hälsoystemen och förbättra servicen till barn.
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### ABBREVIATIONS, ACRONYMS, and EXPLANATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ALD</td>
<td>Affection de longue durée</td>
</tr>
<tr>
<td>ADP</td>
<td>Assistenza Domiciliare Pediatrica</td>
</tr>
<tr>
<td>BACAPH</td>
<td>British Association for Child and Adolescent Public Health</td>
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<tr>
<td>BMA</td>
<td>British Medical Association</td>
</tr>
<tr>
<td>CINAHL</td>
<td>An electronic reference database for nursing and allied health professional research.</td>
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<tr>
<td>CMO</td>
<td>Chief Medical Officer</td>
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<tr>
<td>CRC</td>
<td>Convention on the Rights of the Child</td>
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<td>EAP</td>
<td>European Academy of Paediatrics</td>
</tr>
<tr>
<td>Embase</td>
<td>An electronic biomedical reference database</td>
</tr>
<tr>
<td>EPA</td>
<td>European Paediatric Association</td>
</tr>
<tr>
<td>EU15</td>
<td>European Union member countries prior to 2004</td>
</tr>
<tr>
<td>EU15+</td>
<td>European Union member countries prior to 2014 plus Australia, Canada, Norway</td>
</tr>
<tr>
<td>GDP</td>
<td>Gross Domestic Product</td>
</tr>
<tr>
<td>HBSC</td>
<td>Health Behaviour of School age Children survey (of the WHO, Europe)</td>
</tr>
<tr>
<td>HMIC</td>
<td>Health Management Information Consortium database.</td>
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<tr>
<td>IBSS</td>
<td>International Bibliography of the Social Sciences.</td>
</tr>
<tr>
<td>IHME</td>
<td>Institute for Health Metrics and Evaluation</td>
</tr>
<tr>
<td>ISTAT</td>
<td>Italian Statistical Institute</td>
</tr>
<tr>
<td>MDG</td>
<td>Millenium Development Goals</td>
</tr>
<tr>
<td>Medline</td>
<td>An electronic reference database for biomedical literature (pubmed)</td>
</tr>
<tr>
<td>NCB</td>
<td>National Children’s Bureau</td>
</tr>
<tr>
<td>NCD</td>
<td>Non-communicable disease</td>
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<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NSF</td>
<td>National Service Framework</td>
</tr>
<tr>
<td>OECD</td>
<td>Organisation for Economic Cooperation and Development</td>
</tr>
<tr>
<td>PubMed</td>
<td>An electronic reference database for biomedical literature (medline)</td>
</tr>
<tr>
<td>RAND</td>
<td>Research ANd Development</td>
</tr>
<tr>
<td>RCPCH</td>
<td>Royal College of Paediatrics and Child Health (of the United Kingdom)</td>
</tr>
<tr>
<td>SIDS</td>
<td>Sudden Infant Death Syndrome</td>
</tr>
<tr>
<td>SPZ</td>
<td>Sozial pädiatrischen Zentren</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually Transmitted infections</td>
</tr>
<tr>
<td>TAC</td>
<td>Team Around the Child</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>UN</td>
<td>United Nations</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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</table>
1. INTRODUCTION

When the Industrial Revolution began, many ordinary children lived and worked in near-slavery conditions. Charles Dickens described the short, difficult lives of poor children in Victorian Britain, and through fiction helped fuel a social welfare movement building on the work of influential 19th century scientists and advocates, and on the political and social changes and revolutions in Europe. Edwin Chadwick (1800-1890) for example, used science to improve society and health in England through investigating the effectiveness of the Poor Laws (3). Chadwick noticed that infants born to parents from laboring classes were more than twice as likely to die in early life than children from the gentry or professional classes, and published his findings in 1842. Louis-René Villermé (1782–1863), another of the first great social epidemiologists, described the relation between mortality and life circumstances in Paris (4). Rudolf Virchow (1821-1902) contributed substantially to social medicine by explaining that poverty, illiteracy, and political subjugation were important determinants of a typhus epidemic in Silesia (5). It was becoming clear that economic and political systems that shape life circumstances are vital forces in determining health. In Sweden, Ellen Key’s writings at the turn of the 20th century focused on the welfare of children as shaped by family, domestic circumstances, and education. She understood that children are individuals in a family and a society and that promoting their health and development is crucial to us all. Key's thinking contributed to the children’s rights movement with lasting consequences around the world. These great scientists, thinkers, and writers are especially remarkable because their work brought the plight of children to the attention of politicians, who improved children's lives, welfare, and health through legislation and policy. A similar process of science-led advocacy for health systems strengthening and political change is needed now.

Early in the 19th century, the health of children was mostly of interest to politicians and industrialists because of the need to protect the child labour
force. In the mid 19th century, up to 40% of miners were children, as was a substantial proportion of the workforce in factories and mills (6-8). Industrialists prospered, while many of the children working for them suffered illnesses and injuries, and died. The Factories Act of 1802, also called the Health and Morals of Apprentices Act, was one of the first notable steps in a long process of improving the lives of children in the United Kingdom (9). This law mandated factory owners to improve ventilation and clean their premises at least twice a year. Children were entitled to two changes of clothes, and to share their beds with no more than one other child. Working hours were limited, to 8 hours a day for 9-13 year old children and 12 hours a day for children under 18 years. The 1802 Act also required factory owners to provide care for children with infectious diseases, thus providing a rudimentary occupational health care service. In Britain, by the end of the 19th century, schooling for children under 10 years of age became mandatory.

The early 20th century was considered a great child public health era because of improvements in the upstream determinants of health driven by political, economic and social action, leading to tremendous gains in child health. Indeed the beginning of the 20th century was marked by the passage of an important law in the history of child health and rights: the 1904 Prevention of Cruelty to Children Act (10). The poor health of young soldiers in the First World War and Boer War brought further attention to the need to improve children’s health and fitness. Furthermore the development and popularisation of psychoanalytic theories around the turn of the 20th century highlighted the importance of early childhood in the future functional abilities and happiness of adults. Early studies on child development, notably by John Bowlby who described the first years of life as vital for enabling children and future adults to develop empathy and to form healthy relationships (11). It is unclear whether Bowlby's work was inspired by Ellen Key, but the similarities are striking. Key's writings were particularly important because she recognised the intrinsic value of a child in its own right, not just as a future adult.
The middle to late 20th century can be called the healthcare era, because rapid growth in medical knowledge and technologies stimulated advances in paediatric practice, making it possible to intervene more effectively in many more diseases and problems than ever before. Public expectations of medicine grew accordingly, and inevitably the technical medical model of care failed to deliver all the promised cures for diseases and better health and wellbeing. Concerns about healthcare quality rose up the public and professional agendas. A series of seminal publications such as the World Health Organization's World Health Report in 2000, and the Institute of Medicine's report, Crossing the Quality Chasm, documented health system and health care failures, and contributed to the rising interest in health systems performance (12, 13).

Health systems across Europe are struggling with the processes of structural and organisational reform, attempting to meet the evolving needs of their populations, improve the quality of care that is delivered, and seeking to contain costs. Despite impressive improvements in child health throughout Europe, significant problems remain. It is of vital importance that children’s health services and systems adapt and improve. A strengthened child health system, together with political action on social determinants, is crucial for securing the future health of children and young people. The early 21st century should be the era of health systems. This thesis is a contribution to research about child health systems in Europe.
2. BACKGROUND

The public health tradition has both a rational and a moral dimension. Public health practice can be defined as the process of assuring the conditions for optimal health. There are two broad means by which this is achieved: first, through science to improve understanding of the factors that shape health and disease, using epidemiology, statistics, social science, and biomedicine; and second through public health action to prevent disease, promote health, and provide care, using surveillance and monitoring, population and individual level interventions, and evaluation. These traditional public health functions occur through a variety of structures including governmental and non-governmental organisations, health systems, health services, and academic institutions.

Child health is shaped by multiple diverse determinants in the social, economic, and physical environment, and by health services and systems. Our purpose as child public health scientists and professionals is to improve child health through understanding and strengthening the conditions for children to survive and thrive. Recent changes in health, and in the capacity to improve health have provided new challenges and new opportunities for public health. Addressing the upstream and intermediate determinants of health through traditional public health interventions, adapted to new circumstances, remains an important function of public health. In the UK, public health practice is traditionally described through five functions: health promotion, health protection, public health intelligence, academic public health, and health services public health. The latter, shaping health care better to meet population health needs, is becoming an increasingly important part of public health as the technical capacity of healthcare has improved, while the challenges of delivering safe, effective, and efficient healthcare are increasingly evident. Strengthening health systems for children extends the remit of health services public health, incorporates the skills and functions of public health and children’s medicine, and directs its focus towards population level health gain.
This dissertation fits into the public health tradition through its focus on strengthening health services and systems for children, in the context of wider social determinants of health. The work presented here brings public health and health services together into child population medicine. The purpose of this work is to describe child health problems and assess health services and systems, in order to help shape effective responses to strengthen child health systems and policies in the best interests of children and young people.

2.1 Child health in Europe

The health of Europe's children has improved dramatically in recent decades, and more children survive than ever before. However the current and future lives of Europe's children are being shaped by the epidemiological transition away from predominantly acute and infectious illnesses, towards chronic diseases and long-term conditions including mental and behavioural problems. These new morbidities are shaped in large part by social factors, but the increasingly likely survival of preterm babies, and growing numbers of children with complex conditions including neurodevelopmental, cognitive, and behavioural problems are also factors. These events are happening against a background of rapidly changing European economies, social welfare policies, demography, cultural norms, science, and technology. Furthermore there are profound socioeconomic and geographic inequalities in child health and life chances within and between countries. Health services and systems throughout Europe, and the wider social and economic contexts in which they exist, face tremendous challenges to ensure a healthy and thriving future for children.

2.1.1. Child rights, child health, and the rights of the sick child

The great scientists, writers, advocates and politicians of the 19th century brought about a change in the notion of childhood and its significance. Childhood became recognised as an important stage of life in its own right. A notable achievement of the mid-late 20th century was the United Nations Declaration on the Rights of the Child, which recognised the civil and legal status of children,
describing children's rights to healthcare, education, social and civil services (14). The Convention sets out the conditions necessary to protect and promote children’s health and lives. 194 members of the United Nations (but not the United States and South Sudan) have ratified the Convention. Several countries have established means by which the UN CRC can be translated into national policy and implemented in practice. For example, the UK Royal College of Paediatrics and Child Health has a permanent advocacy committee, and each of the four nations within the UK has a children’s commissioner, akin to Sweden’s children’s ombudsman. Indeed several countries are part of of the European Network of Ombudspersons for Children, ENOC, which works through advocacy to promote children’s rights and the implementation of the UN CRC (15).

The United Nations set out four elements of health care which are necessary for realising the right to the highest attainable standard of health described in the UN CRC: availability, accessibility, affordability, and quality (16). A great deal of the progress in children's health rests on the societal acceptance of children's rights and the importance of childhood. However, by contrast with children’s life circumstances, less attention has been devoted to the rights of the sick child. Health services in many countries are still designed mostly around the needs of adults, and have failed to adapt to the epidemiological transition and changing patterns of health service use and social need in a way that is sensitive to the specific needs of children and young people.

John Rawls, who was in many ways Dickens’ successor, died early in the 21st century. Rawls’ work took forward the same emphasis on social inequality and injustice as Dickens, writing that the principles of justice are the basic structure of society and that every person (child) has equal rights to basic liberties (17). The four essential elements of healthcare described by the United Nations as necessary for realising the health goals of the Convention on the Rights of the Child (CRC) are availability, accessibility, affordability, and quality. Improving these elements is an urgent task and a matter of social justice. A right’s–based approach to strengthening children’s health systems through applying the articles of the CRC that describe children’s rights to protection, provision, and
participation, as shown in table 1, provides a framework and motivation for action (18).

**Table 1. Articles of the Convention on the Rights of the Child that are particularly important for strengthening child health systems**

<table>
<thead>
<tr>
<th>Child rights to Protection</th>
<th>Article 6: Right to life</th>
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<tbody>
<tr>
<td></td>
<td>Article 9: Right not to be separated from parents (except to protect the child)</td>
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<td></td>
<td>Article 19: Right to be protected from all forms of abuse</td>
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<td></td>
<td>Article 20: Right to special attention</td>
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<tr>
<td>Child rights to Provision</td>
<td>Article 24: Right to the highest standard of healthcare</td>
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<tr>
<td></td>
<td>Article 27: Right to a standard of living adequate for a child’s physical, mental, spiritual, moral, and social development</td>
</tr>
<tr>
<td>Child rights to Participation</td>
<td>Articles 12, 13: Right to express views freely, and be listened to</td>
</tr>
<tr>
<td></td>
<td>Article 17: Right to access to information</td>
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<tr>
<td></td>
<td>Article 23: Right for disabled children to enjoy life and participate actively in society</td>
</tr>
</tbody>
</table>

Adapted from: Waterstone, 2006 (18)

Strengthening child health services and systems, together with the macro level determinants of health, should help countries to meet the obligations set out in the United Nations CRC, and their moral responsibilities to children and young people.

**2.1.2. Society and health**

The determinants of health can be described as macro level factors such as social and economic conditions, meso-level health systems and organisation of services, family and community environment, direct pathogenic and salutogenic determinants and micro factors such as quality of care at individual clinician-
patient level, and at the most micro level the individual child’s genetic constitution. Dahlgren and Whitehead described comprehensively and succinctly the determinants of health in a diagram, adapted as shown in figure 1.

![Diagram of determinants of child health]

**Figure 1. Determinants of child health**

*Source: Adapted from Dahlgren and Whitehead, 1993 (19)*

Macro level determinants at national and transnational levels affect social systems such as education, health, political, and economic. Social systems have different defining goals, but their forces interact to create conditions which foster individual and societal health and wellbeing. This is illustrated in figure 2.
The socio-economic determinants of health are also described according to their proximity to illness or disease. Upstream or distal determinants include social and economic factors. Intermediate factors can be both outcomes and risk or protective factors; examples include tobacco, alcohol, obesity, sedentary or active lifestyles, education, and parenting. Downstream or proximal determinants are risk factors that directly cause disease such as bacteria and viruses, and protective factors such as vaccination and hand washing. These factors interact in a complex causal web, some aspects of which are still not fully understood, but which has been diagrammatically represented in several ways, one of which is shown in figure 3.
2.1.3. Poverty, inequalities, and social determinants of health

Poverty and inequalities in wealth are crucially important factors in determining child health. These socio-economic determinants of health are the most upstream factors shaping children's health and life chances. Macroeconomic, fiscal, and social protection policies can provide an equitable foundation for children to survive and thrive. Political choices, therefore, are fundamentally important for child health.

Child poverty can be defined in many ways but a commonly used metric is the proportion of children who live in households with an income that is less than 60% of the national average (22). Thus, it is immediately clear that national fiscal policy directly affects child poverty and therefore children's life chances, since family income and security can be increased through redistributive fiscal policies, tax exemptions, social benefits and services. Overall rates of deprivation vary considerably between countries, but there are also substantial differences within countries as to which ages and population groups suffer most. The lowest

Figure 3. A causal web illustrating how socio-economic factors relate to health

Source: Adapted from Cattaneo, 2012 (21)
rates of child poverty and deprivation tend to be in the Nordic countries, while the highest rates are often in Southern and Eastern European countries (23). While child poverty rates vary between countries, a very frequent finding among European countries is that the probabilities of children living in, or who are at risk of, poverty and social exclusion are greater than the rest of the population. Thus, for example, the proportion of the total population at risk of poverty or social exclusion, among EU27 countries in 2011, was 24%, contrasted with 27% of children aged 0-17 years, but only 21% of the population aged 65 years or older (24). Individual country differences are revealing. In the UK, children are disproportionately disadvantaged compared with other age groups, and to a larger degree than most other countries (25). The disadvantages that children face through growing up in poverty may be compounded if there are other difficult social circumstances. For example, in many countries children living in lone-parent households may be at even greater risk of poverty, as is having unemployed or belonging to migrant, ethnic minority, or Roma populations (21, 26).

Countries differ in their approach to child poverty reduction, for example as to whether support is provided as direct expenditure on services, or as benefits in kind. For example, Denmark and Ireland are among the highest overall spenders on families and children, as a percentage of GDP, but Ireland distributes more through cash transfers (benefits) while Denmark spends more on services (24). The UK launched a poverty reduction strategy in the late 1990s with a specific emphasis on helping children and families. The strategy had three related components: promoting work and making work pay; increasing financial support for families with children; investing in programmes and services for children. The goal was to end child poverty in 20 years, and halve it in 10 years. The first five years were impressive; Britain’s relative child poverty rate fell, while in much of the rest of Europe it remained stable or increased (27). The potential impact of policy is important to note because social determinants begin affecting child health before birth, and a social gradient is demonstrable for many child health determinants and conditions. Social gradients in pregnancy outcomes have been described in many European countries until the early 2000s and more recent data from Finland, Germany, Italy, Netherlands, Spain, United Kingdom
and the Nordic countries indicate that these differences have persisted (28). Infant mortality is therefore often used as an indicator of health system performance and wider socio-economic factors. There is also a social gradient in measures of risk, disease incidence and prevalence throughout the early years of life. For example child overweight and obesity are related to adverse social and economic conditions, rates of asthma are higher among children from low income families, and many other conditions such as cerebral palsy and other forms of physical disability, and most forms of mental health problems, are associated with adverse socioeconomic conditions (21, 29, 30).

The effects of social and economic inequalities can be traced through each stage of the causal web, and throughout the life course. Social inequalities in infant and child mortality are consistently reported in all countries, though the mortality gradient tends to be steeper in Southern than in Northern Europe (31). Mortality rates for children in the pre-2004 European Union countries (EU15) have dropped precipitously. Although the differences between countries have narrowed, considerable variation remains. If the EU27 mortality rate for children 0-14 years old were as low as Sweden’s rate, there would be over 12,000 fewer deaths each year (32). The reasons for the variations between countries are multiple but since child mortality rates are associated with major socio-economic factors, explanations are likely to include national wealth and levels of inequality, social spending, generosity of family policy, and equitable accessibility of high quality health care. There are strong associations between child mortality rates and income inequality, national wealth (as measured by gross domestic product) spending on social protection policies, and generosity of family policies (32, 33). The associations between child survival and economic and social policy are important, and there are large numbers of children in Europe living in poverty or material deprivation (34). Economic and social policies can strengthening conditions for health, and thereby can save lives.
2.1.4. Determinants and intermediate outcomes of child health

Most of the intermediate determinants of health and outcomes can be mitigated by legislation and public health policy at international, national, or local levels, and through health systems and services policy and practice. Since the challenges health systems face are similar, variations in outcomes among children and adolescents in Europe, suggest scope for learning from other European country experiences.

Obesity

The prevalence of obesity among children and young people in Europe is increasing, reflecting a complex interplay of factors culminating in an obesogenic environment in which it is often easier to become overweight or obese than it is to maintain a healthy weight (35). Prevalence rates for overweight and obesity in children under 4 years range from 11.8% in Romania, to 33.2% in Spain; countries within this range vary but, in general, Mediterranean countries tend to report higher prevalences than those in Northern and Eastern Europe. Among older children between 6-9 years, on average 24% are overweight or obese (21). Self-reported data from the Health Behaviour of School-age Children (HBSC) study describe further and detailed variations between countries and regions. HBSC showed that boys are more likely to be overweight or obese than girls, and that self-perception of overweight or obesity is more prevalent than that defined by body mass index in western and central Europe, but not eastern Europe, suggesting body-image concerns in the West.

Obesity risk may begin from the earliest stages of development; for example through epigenetic changes that may affect later susceptibility to obesity (36). However, without doubt, the increasing prevalence of overweight and obesity reflects the changing environments in which children live and grow up. An obesogenic environment dominates in wealthy countries, with energy dense food and drink, often intensively marketed to children and, to lesser degree,
fewer opportunities to exercise and physical activity (37, 38). Children living in socially and economically disadvantaged positions are at greater risk of obesity and its health consequences, than their wealthier peers (39, 40).

The European Community’s Common Agricultural Policy and free trade agreements, together with increased global trade and advances in food production and distribution, have helped create circumstances whereby the food industry has become increasingly dominated by large corporations promoting energy dense products at inexpensive prices (41). Many studies have shown that few children eat the WHO recommended daily allowance of fruit and vegetables (42). Furthermore, low levels of physical activity in children also are associated with overweight and obesity, higher blood pressure, and lower high density lipoprotein (HDL) cholesterol levels (43). There are other benefits of physical activity besides obesity avoidance. Children who are more physically active are thought to cope better with symptoms of anxiety, and to perform better academically at school, and to adopt other healthy behaviours such as avoiding drug and alcohol use (44). Around half of 11 year olds in Europe do not engage in sufficient physical activity for health, and the proportion increases through adolescence (45). The HBSC survey reported that only 23% of 11 year olds, 19% of 13 year olds, and 15% of 15 year olds engage in at least one hour of moderately vigorous physical activity per day which is the recommended amount of daily exercise based on a review of the literature (46, 47). National and European Union wide policies can help mitigate the effects of the growing obesogenic environment for Europe’s children.

**Tobacco**

Tobacco is responsible for more adult deaths in the EU than any other single cause, and is one of the main causes of disability (48, 49). Smoking behaviour usually becomes established in adolescence, and smoking prevalence remains high among adolescents in many countries (21, 46, 50). On average, 30% of 15 year olds report first smoking at the age of 13 or younger, though there is a wide variation between European countries ranging from 7-65% (51). On average, 1% of 11 year olds in Europe smoke at least once a week, as do 6% of 13 year olds, and 19% of 15 year olds, but again there are wide variations between countries.
There has been a trend towards increasing smoking rates, especially between 13 and 15 year olds, and smoking rates among girls are higher than among boys (51). Likelihood of smoking is associated with family breakdown, with parental smoking, and with low family cohesion; conversely, strong family relationships and positive peer and friend relationships are protective. As with many health behaviours, there is an association with socioeconomic status. This also applies to exposure to environmental tobacco smoke. Tobacco use in pregnancy affects fetal development, and may also increase the risk of intra-uterine growth retardation, low birth weight, and pre-term birth (52). In several countries, social disadvantage is consistently associated with more frequent pre-natal and post-natal exposure to tobacco (53).

Alcohol

Alcohol use causes damage to children, young people, and to unborn children. Alcohol is responsible for 11% of deaths in men, and although only 1.8% of deaths in women, there are other profound effects on women which directly or indirectly affect children (28). For example, alcohol intake through pregnancy can cause fetal alcohol syndrome. Alcohol can also cause family and social problems through poverty, intimate partner violence, and family breakdown (21). The prevalence of alcohol use increases significantly during adolescence in almost all countries and, in general, boys drink more often, and get drunk more often, than girls, although the differences are narrowing rapidly in many countries. 2% of 11 year olds in a survey of European countries, have been drunk at least twice, a third of 15 year olds have done so, and 21% drink alcohol at least once a week (46). There is a weaker association between alcohol use and affluence compared with tobacco, but family environment does affect the likelihood of alcohol use(46).

Social attitudes, families, and growing up

Family policy varies between European countries, and the impact on family life and children is important. Family life influences children’s health, wellbeing, and educational achievement, with effects that are independent of socio-economic status. The relationship between parent and child, and the wider family, are important influences in a child’s life, shaping health, wellbeing, and development
in the early years and beyond. The associations between family life and health are likely to be causal, given the consistency of the findings in many different populations, at different times, the strength of the observed associations, and the evidence of dose-response relationships (54-57).

Although social attitudes to family and children vary across Europe and are related to culture and religion, many countries have seen profound changes in family structure, attitudes, and parenting styles over recent decades. Many of these social changes are shaped by policy(21). Women's status, their education, and their role in family and society, have important influences on child health and well-being, starting from reproductive behaviours and outcomes, with longer term and intergenerational effects(58). Where women have a higher social status and a more central role in decision-making, greater resources, at both public and household levels, tend to be directed to child nutrition, welfare and education, ultimately contributing to child health outcomes(58).

The role of fathers in promoting child health is less well described, although strong family ties are important for promoting child health and development. For example, children from single-parent families may have a lower sense of well-being and worse educational outcomes, although of course there are many exceptions. For example, in the USA, the risk of developing behavioural problems, of having to repeat school years, and leaving school prematurely are twice as high as in two parent families, and the risk of teenage pregnancy is increased six fold. However approximately half of these differences can be attributed to the greater risk of poverty after family breakdown(59). Social policy for families therefore directly affects outcomes for children. This is demonstrated in Sweden, for example, where there are more single parent households than in the United Kingdom, but there are many fewer Swedish children in poverty.
2.2. Health systems

A health system comprises all the organisations, institutions, and resources that are explicitly dedicated to health. The World Health Organization (WHO) defines the objectives of a health system as improving health, responding to legitimate expectations, and fairness of financing (12). Health systems therefore include governance, financing, workforce, information systems, technologies, and health service delivery.

2.2.1. Health systems assessment

Public health as a profession is evolving to meet child health needs in the 21st century; addressing the upstream and intermediate determinants of health as before, but also shaping health systems and health care better to meet population health needs. Health systems research generates evidence for how to strengthen health systems, and how better to deliver system-wide interventions at scale. However, research on health systems is at an early stage of development compared with biomedical research, and one reason is because the research methods for answering questions in this field are different (60). Methods are different, by necessity, because the causal chain can be very complex and often poorly understood, and it can be difficult to determine what and how to measure. The question of attributability is therefore also challenging to answer. The complexity of health system assessment is diagrammatically represented in figure 4.
Figure 4. Health systems: the complexity of determining causation

Figure 4 illustrates some of the challenges in assessing health systems; there are many variables to measure, and it can be difficult to determine causation, and therefore attributability. Four dimensions of health system performance are commonly evaluated: health improvement (for individual patients and entire populations), responsiveness (dignity, autonomy, access to support), equity, and efficiency. These neatly overlap with the four elements of health services needed to realise the United Nations’ aim to secure the highest attainable standard of health: availability, accessibility, affordability, and quality. Measuring these dimensions of performance often requires different research methods from clinical trials which test technologies and medicines, often in ideal and
standardised environments. Health systems operate in highly complex environments. Health systems interventions and policies are examples of complex public health interventions, with extended causal chains, multiple interactions between components, and numerous intervening variables that can affect the outcomes (61). Evaluating complex public health interventions is different from conducting a clinical trial, for example of a drug. So while the strength of evidence in biomedical research may be loosely judged according to a hierarchy, with randomised controlled trials as the gold standard, health systems and policy research is different. Health systems research may be required to produce recommendations on the basis of "best available knowledge rather than the most desirable evidence" in order to help us understand how well systems work, and what should be done differently to strengthen health system performance (62). Health systems research therefore is a transdisciplinary field defining new methods and standards for evaluating evidence and making recommendations.

The WHO set about measuring to what extent health systems meet their objectives, ranked countries by performance and goal attainment, and published their findings in the 2000 World Health Report, Health Systems: Improving Performance(12). There are several remarkable findings in this report, and important questions arise as a result. It is immediately evident in the WHO health systems report that western European health services perform very well in the global context. Overall health system performance and goal-attainment for high-income European countries are very good and they occupy the top places in the ranked list, in stark contrast to low and middle-income countries that are towards the bottom of the list. By comparison, the rich countries seem to have little to worry about, but in its local context the wealthy developed world still has significant and difficult problems to solve. Health systems research traditionally focuses more on low and middle income countries than on wealthy countries, perhaps inevitably because the scale of challenge is much greater(63). As European child health systems research develops, it is important to ensure that
the problems of high-income countries are not neglected in the face of comparatively more substantial global child health threats.

European health systems research developed appreciably from the mid 1990s when the European Observatory on Health Systems and Policies established a programme of research, publishing a variety of studies on health systems. The Observatory largely focused on adults, until the 2013 publication of European Child Health Services and Systems: lessons without borders, co-authored and edited by Wolfe and McKee (64, 65). Importantly, UNICEF established an office of research known as Innocenti, to support research about child health and policy, and to provide advocacy and leadership for children’s rights. From 2000 onwards, UNICEF Innocenti has published reports, papers, and books about child health and wellbeing. UNICEF Innocenti has made important contributions to European child health research, and one of their particular strengths is in cross-country comparisons of wellbeing, including aspects of health, and determinants such as poverty and inequality (66). A notable early example of work to understand child health, health service and system performance in the UK was The Court Report, which makes reference to the European context in its findings. This seminal work, published in 1976, described suboptimal health outcomes among children in the UK compared with a small selection of European countries, documented a pattern of evolving health needs and social circumstances, and noted that British child health services differed from European models of care (67, 68). The United States has made substantial contributions to child health systems and policy research, through organisations including the Institute of Medicine, Institute for Healthcare Improvement, RAND, and the Commonwealth Institute, and by individuals such as Donald Berwick, Charles Homer, Rita Mangione-Smith, Sheila Leatherman, and Neal Halfon, who together with their colleagues have led the way in children’s healthcare, health systems, and policy research (69-73).

While there has been notable progress in health systems research for the general population, and for child health systems in the USA, a glaring deficit in European child health systems research remains: there are no systematic comprehensive
assessments of healthcare quality or health system performance specifically for children and young people in Europe. Cultural and historical contexts and health systems are different in Europe compared with the United States, so it is important that European child health systems are assessed specifically with reference to the population they serve. Moreover children’s health needs and the way they use services and health systems is different from adults, as will be described in the following section.

2.2.2 Child health systems in an adult context

Just as was the case for medicine in the early 20th century, health systems research has tended to take an overview of the whole population and all ages, rather than focusing attention on the distinct needs of children and young people. Children’s health needs change with their developmental stages, and are distinct from adults’ health needs in many ways, as summarised in box 1 (74). Each part of early life brings distinct problems, illnesses, and developmental concerns: preterm infants, term newborn infants (0-28 days), infants and toddlers (>28 days to 23 months), children (2-11 years), adolescents (12-18 years), and young people (up to 25 years). Although children and young people may seem to have similar health problems as adults, there are many specific childhood illnesses, and those they have in common with adults often manifest illness differently, so require different approaches to disease prevention, diagnosis, treatment, and support. Children also differ from most adults in their dependence on parents and carers to seek health care, communicate their problems, administer interventions, and communicate their views on the experience of care. Child protection and safeguarding forms an important part of children’s health care. Adults and the elderly frequently suffer multiple co-morbidities, whereas this is rare for children. Policy responses should reflect these differences in order to meet the specific and distinct needs of children and young people. Thus, while it may once have been more appropriate for paediatrics to be part of adult healthcare and routinely delivered by the same doctors, children's health needs are now recognised as distinct from adults, and
paediatrics has grown into a sophisticated specialty with a discrete and growing knowledge base. However despite this progress, health services have failed to adapt adequately.

**Box 1. How children’s health needs differ from those of adults**

Adapted from Forrest, 1997 (74)

Despite the important differences between children and adults, health service planning, evaluation, and children’s health system research are yet to come into their own. This is perhaps not surprising since health systems are struggling to meet the challenges of an ageing population and increasing burden of chronic and often multiple long-term conditions. Accordingly, international comparisons of health systems focus heavily on measures of adult health which may not apply to children. For example, an important outcome for children with long-term conditions may be inability to attend and participate fully in school, compromising their future development and potential. Such meaningful outcomes are rarely measured. Instead, national quality assessment and healthcare regulatory systems report waiting times for operations such as hip
replacements and cataracts that matter a great deal for adults and the elderly, and say less about how well health services perform for children.

Health systems research has grown in recent decades, with a variety of national and international research initiatives and publications(64, 66, 75, 76). Consistent with these developments, there are several UK institutions that measure aspects of quality of care, usually focusing on specific institutions or diseases and examine quality from a micro perspective. There are some comparisons of regions or providers in the UK, but there is very little about either England or the UK in a European context (although reports from Scotland and Wales are more likely to refer to wider contexts). While there are notable examples of child health service and system research as described earlier, in Europe this remains a field in early stages of development. However a decade or more of global health systems and policy analysis and comparisons has given enough time to reflect on the state of the field, and formulate lessons to refine and improve future work in developing European child health systems research (77). There is a clear need to develop an international consensus on a conceptual framework, indicators and measures, and specifications for data to support robust child health systems analysis for Europe.

2.2.3. Developing European child health systems research

The goals for advancing child health systems research are to improve knowledge and understanding, and to provide better quality information for policy makers and practitioners, in order to improve child health. A conceptual framework is a useful start point. Local context must be accounted for, and clarity of definitions and boundaries of health systems are important. Finally, health system performance indicators that are valid, reliable and comparable, and a means of assessing implications for policy and practice are crucial (77). Making progress in European child health systems research will require building a conceptual framework and performance indicators and measures for evaluation.
2.2.4. Conceptual framework for health systems

A conceptual framework for health systems research is helpful in defining the parameters of a health system. Wide boundaries that include most health determinants provide a comprehensive view of everything that influences health, and helps identify interactions between sectors. It is however difficult to attribute causality and hold sectors to account. Narrow health system boundaries that encompass health care alone can make it somewhat easier to attribute outcome to intervention, and hold people to account, however many important variables will not be included, and it is still difficult to exclude other effects on outcomes (77). Not surprisingly most quality assessments focus on the micro level, as do most quality improvement initiatives. It is all the more important therefore to devise methods for summarising complex systems information, and for detecting and describing important contextual issues for health systems.

There are several health systems frameworks available (77-80). However the OECD Health Care Quality Indicators Project has devised a conceptual framework that is especially useful because it encompasses descriptive elements and it can be used as an assessment framework (81). It encompasses the four broad dimensions of health system performance, and elements of health services described by the UN and outlined earlier. A version adapted for child health systems is shown in figure 5. Health status, determinants, and health system design (the first three tiers) provide an overview of health progress. The fourth tier of the matrix is health care system performance, and uses the Donabedian structure, process, outcomes dimensions describing the relations between health, quality and cost of care, (shown from right to left) (82). Healthcare needs are represented through a life-course approach: staying healthy, getting better, and living with illness or disability (including paediatric palliative care where necessary). Health promotion is described both through staying healthy and through the link between non-healthcare determinants and healthcare performance. Macro, meso, and micro level determinants are indicated.
This adapted conceptual framework helps to describe healthcare in the context of a health system and wider determinants of health, in order to assess performance.

Figure 5. A Conceptual Framework for assessing health system performance

Adapted from Arah, 2006 (81)
2.2.5. Health system and healthcare services measures

Health system assessment is about determining how well a health system meets its key aims. The WHO definitions of health system aims are broadly about goodness and fairness of health. Goodness is delivering the best attainable level of health, and fairness is about achieving the smallest feasible differences between individuals (12). As mentioned previously, commonly measured dimensions of health system and service performance include health improvement, health care quality, responsiveness, service equity and efficiency. It is important that measures are meaningful for children and young people.

The ability to learn through investigating the diversity of approaches to health care in Europe is severely impaired by the lack of appropriate, valid and comparable information to undertake comparisons. In some countries, such as Germany, even basic data on immunisation levels are estimates based on ad hoc surveys. A compendium of child health indicators enables some comparison but existing indicator sets need to be supplemented and based on reliable and uniform systems for collecting and analysing data, to allow comparison of the quality of health services for children across Europe (83). Such a development would greatly facilitate efforts to improve services.

Population studies on health and wellbeing often do not include children and results are not generalisable to children(84). Research on health services does not always match population health need or demography. For example, only 5% of all research on any form of cancer relates to children (85). It is estimated that between 11% and 80% of all paediatric prescribing is off-label, in part because of the paucity of clinical trials in children (86). What research is undertaken focuses disproportionately on the most complex conditions. Between 2000 and 2009 there was an 18% increase in Cochrane systematic reviews relevant to children, yet only a 2% increase in reviews applicable to childhood illness in primary care. Although non-drug interventions play an important role in
primary care they were the focus of less than half of the reviews evaluated (87). Only one-tenth of reviews focus on interventions for psychological conditions, despite the growing burden of mental health problems in children and adolescents (88). By contrast with Europe, there have been several systematic attempts to measure the volume and quality of child healthcare in the USA (89).

To examine health systems and make meaningful comparisons of the health needs of children and the ways in which health systems respond to them, requires appropriate and comparable data. Some of the earliest steps towards this goal were taken by those charged with monitoring compliance with the UN Convention on the Rights of the Child (UN CRC), which places the child's interests at the centre of policy. A project within the European Union’s 7th Framework Programme, involving 29 countries, has compiled an inventory of child health research in Europe, identifying emerging themes for future EU funding priorities (90). Europe has the infrastructure in place to conduct research to answer important questions in child health, such as European networks of longitudinal pregnancy and birth cohort studies. Some countries, for example Denmark, Finland, and Sweden have benefitted from the ability to link multiple data sources from primary and secondary care and social services, but this is unusual. Practice based research networks have yielded promising results in the UK, Italy and some other countries (91). The StaR in Child Health initiative is intended to enhance the quality, ethics and reliability of paediatric clinical research and has recently published its first six standards (92). Similarly, the EU-funded Global Research in Paediatrics (GRiP) Network of Excellence was launched in 2011 to facilitate the safe use of children's medicines and create international standards for paediatric research (93).

There are other initiatives such as the OECD’s Healthcare Quality Indicator Project, which includes some indicators relevant to children, such as immunization cover; the World Health Organization’s Health for All database; and the European Collaboration for Healthcare Optimization (ECHO) project which will facilitate health system research using hospital databases but with limited information on children (94-96). In addition, several time-limited
research projects have provided comparative information that can inform indicator development, such as CHILD which in 2002 produced key child health indicators to complement perinatal indicators (PERISTAT) covering the life course, together with aspects of primary, secondary and tertiary prevention and policy (97). The CHILD indicators include traditional measures of mortality and morbidity, and data items from existing EU-wide surveys, such as the Health and Behaviour of School-Aged Children, as well as novel indicators such as hospital admissions for long bone fractures (44). Finally, the EU has agreed a selection of structural indicators on measures including access to care for vulnerable children such as asylum seekers, and indicators for the protection and promotion of child rights (98).

Developing indicators for children’s health systems research is particularly challenging because of the unique issues of children’s health and lives, the 4 D’s: developmental change, dependency, differential epidemiology, and demographic patterns, reflecting children’s distinct and differing health needs described in box 1 (74, 99, 100). It is also important to ensure that indicators are transferable between countries. A few countries have made attempts to develop measures for examining the quality of primary care, for example management of ambulatory-sensitive conditions and avoidable hospital admissions. In Spain, there is a list of primary care-preventable hospital admissions including several relevant to children, such as immunisation-preventable diseases and pneumonia(101). In Italy, frequency of antibiotic use and choice of recommended drug has been used as an indicator of quality of paediatric care and of professional continuing education (102). The UK has quality indicators for some primary care services, linked to a general practice pay-for-performance system, although less than 3% of indicators are relevant to children (103). New indicators for health outcomes among children and young people in England, including some specifically for aspects of primary and secondary care, will now supplement existing ones (104). The Dutch College of General Practitioners developed 139 indicators from 61 clinical guidelines including several for children relating to asthma, non-traumatic knee disorders, otitis media with effusion, and fever (105). Reflecting a growing recognition among international policy makers of the importance of reducing avoidable admissions, the UK NHS Outcomes Framework includes a
reduction in unplanned hospital admissions for children's chronic diseases and lower respiratory tract infections as health improvement targets. Although these initiatives signal a growing awareness of the importance of child health research, there is a need for individual countries and EU-wide bodies to review investment in child health and health services and systems research, focusing particularly on areas of need such as quality measurement in primary care and studies to compare first contact models. There are areas of child health systems that are more unexplored than others. Little work has been done, for example, on developing measures of health system responsiveness for children and young people. A selection of health system measures that may be useful for child and adolescent health is shown in table 2.
### Table 2. Health system measures

<table>
<thead>
<tr>
<th>Health System Dimension</th>
<th>Measures</th>
<th>Comments</th>
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<tbody>
<tr>
<td><strong>Population health</strong></td>
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<td></td>
<td>Aggregate data on health status</td>
<td><em>Broad perspective, includes healthcare and other risk factors and determinants</em></td>
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<td></td>
<td>Life expectancy</td>
<td><em>Difficult to attribute changes in health to a policy</em></td>
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<td></td>
<td>Mortality rates</td>
<td><em>DALYs use weightings which may be controversial</em></td>
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<td></td>
<td>Disability-adjusted life-years</td>
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<td>Avoidable mortality</td>
<td><em>More specific perspective on healthcare quality</em></td>
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<td></td>
<td>Amenable mortality</td>
<td><em>Variation in definition and coding practice limits comparability</em></td>
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<td></td>
<td>Disease specific mortality</td>
<td><em>Small numbers</em></td>
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<td></td>
<td>Tracer conditions</td>
<td><em>Context is important eg disease prevalence</em></td>
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<td></td>
<td>Disease survival</td>
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<td>Morbidity</td>
<td></td>
<td><em>Potentially specific focus on health outcomes and service delivery outcomes</em></td>
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<tr>
<td>Indicators</td>
<td></td>
<td><em>Registries are not well developed</em></td>
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<tr>
<td>Incidence</td>
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<td><em>Reporting bias</em></td>
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<td>Prevalence</td>
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<td><em>Notification practice variation</em></td>
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<td>Health service use</td>
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<td><em>Representativeness</em></td>
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<td><strong>Health service outcomes</strong></td>
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<td>Health service quality measures</td>
<td></td>
<td><em>Potentially specific focus on service delivery outcomes</em></td>
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<tr>
<td>Disease specific outcome measures</td>
<td></td>
<td><em>Measuring the contribution of healthcare to health is challenging</em></td>
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<td>Case fatality rates</td>
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<td><em>Comparability of services</em></td>
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<td>Complication rates</td>
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<td><em>Comparability of populations</em></td>
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<td>Patient-reported outcome measures</td>
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<td><em>Small numbers</em></td>
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<tr>
<td>Avoidable admission rates</td>
<td></td>
<td><em>Many quality measures are of process rather than outcome; both have benefits and drawbacks</em></td>
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<td>Standardized hospital mortality rates</td>
<td></td>
<td><em>Data quality and availability are challenging</em></td>
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<tr>
<td>Screening rates</td>
<td></td>
<td><em>International comparisons are challenging due to different organisational practices and reporting conventions</em></td>
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<td><em>Most healthcare quality measures are for adults and may not be relevant or generalisable for children.</em></td>
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<td>Dimension</td>
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<tr>
<td><strong>Equity</strong></td>
<td>Health</td>
<td>*Equity indicators are subject to limitations in availability and comparability</td>
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<td>Service access/use</td>
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<td>Financing</td>
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<td>Responsiveness</td>
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<tr>
<td><strong>Financial protection</strong></td>
<td>Catastrophic payments</td>
<td>* This dimension is in early stages of development. At present, direct payments for healthcare are used as a measure indicating financial protection.</td>
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<td></td>
<td>Out of pocket payments</td>
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<td>Index of fairness of financial contribution</td>
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<tr>
<td><strong>Responsiveness</strong></td>
<td>Dignity</td>
<td>*Responsiveness as a health system characteristic has not been widely studied for children, and for adults definitions and measures are not yet agreed.</td>
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<td>Autonomy</td>
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<td>Clarity of communication</td>
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<td></td>
<td>Prompt attention</td>
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<td></td>
<td>Quality of surroundings</td>
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<td>Access to parent and family support</td>
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<td></td>
<td>Choice of provider</td>
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<tr>
<td><strong>Efficiency</strong></td>
<td>Avoidable hospital emergency department contacts</td>
<td>* Although efficiency is an important dimension, measures are not well developed for children. Defining and costing inputs and outputs is challenging, making comparisons even more so.</td>
</tr>
<tr>
<td></td>
<td>Average length of stay</td>
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<td>Unit costs</td>
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<td></td>
<td>Cost-effectiveness per intervention</td>
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Adapted from Smith, 2012 (77)
Future challenges include devising positive indicators of child health to complement those focusing on health deficits. Developing indicators for complex conditions is also important since they often require interventions delivered by multiple agencies acting in partnership, requiring measures that are sufficiently sophisticated to reflect all these contributions. It will also be important to develop indicators that measure the quality of services provided to especially vulnerable children and young people, such as those who are victims of maltreatment, have mental illness, or disabilities, or those who live in the care of State social systems. Some of these indicators are being developed in EU-wide projects (98).

2.2.6. European child health system performance assessment

How well do health systems meet their aims for children in Europe? A preliminary systematic search of published research literature about European child health systems and services research revealed small numbers of descriptive and analytical studies, most addressing a single service or specific aspects of health services or systems in one country. With a few exceptions, comprehensive and comparative child health systems analysis for European countries is still in early stages of development (65, 106, 107).

A comprehensive analysis of children's health systems performance would encompass the domains outlined in figure 5. However as described earlier there is no validated or agreed comprehensive set of child health system measures. If we use the conceptual framework in figure 5, as a guide for describing the health system boundaries for examination, a reasonable start point would be healthcare performance. Indeed, health services are an important, and modifiable, determinant of child health. But how much does healthcare contribute to population child health? Clearly health services are intended to improve an individual child’s health, but many of the things that affect children's health and wellbeing lie in the wider health system and beyond. This is a long-debated subject, and views, which are often highly polarized, depend on the perspective
taken in examining the question. Thomas McKeown, writing in the mid 1970s, showed that most of the decline in tuberculosis that had happened in the previous century predated the use of antibiotics for tuberculosis. McKeown suggested that improvements in social conditions, rather than healthcare, led to reductions in deaths from tuberculosis (108). Ivan Illich went further, famously criticizing healthcare for the damage it can cause to people (109). More recent assessments agree that medicine contributed rather little to the decline in mortality before the mid-20th century(110). However there have been significant changes in the last 50 years or so. Paediatrics has developed into a sophisticated medical specialty with the ability to intervene effectively in many more diseases and problems than ever before. Moreover, as population health has improved, the marginal contribution of healthcare to health inevitably has increased. Even so, the relative importance of healthcare is likely to be somewhat tempered by the epidemiological shift, which is occurring as infectious diseases are giving way to chronic diseases and long-term conditions, many of which are strongly influenced by lifestyle factors. There have been numerous attempts to quantify the health gain attributable to healthcare, with answers ranging from 20-40%, but it seems that none have looked specifically at child or adolescent populations (111).

Much of the literature and discourse on assessing the contribution of health care to health focuses on aggregate measures of population health such as mortality. This is perhaps inevitable because mortality data is more readily available and reliable than morbidity data. Mortality data gives an incomplete, but important, indication of child health status and health system need, and gives a very high level view of overall health systems functioning. Trend data comparing all cause or cause-category rates between countries can provide an indication of health system performance. Differences in coding practice for recording cause of death, and in definitions, for example of stillbirth, between countries can make comparisons especially challenging. Furthermore, mortality alone gives an incomplete impression, especially for children. This is partly because the numbers are small, so random variability can be large. Examining mortality trends over several years can improve reliability. Another reason why mortality
is an incomplete measure of health system functioning is because the value of health care for children extends beyond saving life. Healing, relieving suffering, improving quality of life are also essential parts of health care, albeit more difficult to measure. The concept of health care amenable mortality has contributed substantially to the technical capacity for health service evaluation and comparative assessment for the adult and the elderly population, and furthermore to the question of how much healthcare contributes to population health (112). However this method is of limited use for children's health services because the number of deaths is small, so interpretation is difficult or impossible. Still, avoidable mortality is a useful concept and there are two broad ways it can be useful for child health. The first is by individual case audit. This method has been put to use effectively in audits and enquiries in England, for example by the Confidential Enquiry into Maternal and Child Health in England, and by Child Death Reviews which are now standard practice in England and published at regular intervals providing data for service improvement (113, 114). A confidential inquiry into child deaths in the UK found “identifiable failure in the child's direct care” in 26% of deaths, with potentially avoidable factors in a further 43% (115). Errors by staff with inadequate paediatric training or supervision were common. Thompson and colleagues found that half of children subsequently found to have meningococcal infection are sent home from the first consultation, and failures or delays in diagnosis has cost over £20m (€24m; $33m) in legal settlements in the past 12 years (116, 117). Around 75% of children's asthma admissions could have been prevented with better primary care (118). The second way that the concept of avoidable mortality can be useful for the child population is by examining death rates from illnesses that highly developed European health systems ought to be able to prevent. This latter method is potentially more specific, but requires valid comparable data.

Morbidity data is scarce and often unreliable. Disability-adjusted life years (DALYs) tell us something about what illnesses affect children, causing them to experience problems and suffering, thereby providing evidence both about need and about system performance. Disease prevalence measures could also indicate
health service need, but there are few examples of regular prevalence studies or disease registries across Europe. National and international surveys of health and wellbeing status can be helpful, but may be subject to bias.

Country level measures of healthcare processes can be helpful micro and meso indicators of care quality and delivery system design. For example, in the UK over a third of short stay admissions in infants are for minor illnesses that could have been managed in the community (119). Furthermore, although there is much variation across Europe in the institutions and organisations involved in implementing services for children and adolescents with mental health problems, it is estimated that only a small proportion of children and adolescents who need help receive it from existing services, so measuring access to care is an important component of health systems assessment (28).

The WHO, OECD, and Institute for Health Metrics and Evaluation (IHME) provide regularly updated, validated, and useful data on country and regional mortality, morbidity, and risk factor rates, data on other health systems inputs such as workforce and hospital bed numbers, and other social and economic variables such as gross domestic product (GDP). Despite the multitude of potential data sources, measuring quality of healthcare for children and young people, as part of comparative health systems analysis, is not yet a sophisticated field. The changes in the diseases, disabilities and problems that affect children represent a shift in their needs for health care, and measures of healthcare quality must reflect these changes. Quality is still difficult to define, and challenging to measure. Most existing measures of care quality determine whether care has been received, rather than the quality of care. Comprehensive quality measurement frameworks have been proposed, but are yet to be widely implemented or validated across countries (72, 120). Currently most quality assessments of healthcare rely on measures of health system performance for the whole population, or periodic inspections of particular services such as children’s hospital care; or for specific diseases, rather than comprehensive assessments of health system functioning for children (121-125). For example, in the UK, national audits of quality and consistency of care for diabetes and
epilepsy demonstrate that the quality of care delivered by children’s health services is variable and, in some, instances poor (122, 125). Research in several European countries suggests that up to two-thirds of hospital admissions among children with asthma could have been avoided with better preventive care, such as the use of asthma action plans, education on prevention of exacerbations, and reduction of triggers and risk factors such as parental smoking (126, 127). These examples are useful and important contributions, but still do not represent a comprehensive examination of healthcare quality or health system function.

Child health systems assessment is in early stages, but it is clear that while there have been great successes in European child health in recent decades, many health system responses to evolving health and social needs and advances in knowledge and technical ability have been inadequate. For example, although there is greater awareness that the foundations for physical health, cognitive development, and social and emotional wellbeing are established early in life, there has been a systematic failure fully to translate this knowledge into policy and practice. Investment in the early years is effective and cost-effective for population health gain, yet government spending on health, education, and care does not always reflect this fact. Furthermore, health services and systems should be planned carefully on the basis of current and evolving health care need to ensure high quality as systems adapt to the epidemiological transition. At present, health service planning often relies on routinely collected administrative data, usually based on previous patterns of health service use rather than normative and expressed need for health care. Future health service provision is commonly planned on the basis of this type of tautological information. The World Health Report 2008 describes health systems’ responses as “too little, too late, or too much in the wrong place” and argues that a whole system solution, rather than temporary and piecemeal remedies is required, involving society beyond the health sector (128).

Health systems strengthening efforts have become a vital part of global health, but it is clear that renewed efforts are required. Ensuring universal health coverage is the paramount challenge in many parts of the world, while in Europe
coverage is generally good, so the priorities and goals are different. Delivering health care that meets needs and optimises the developmental potential of children and young people is a primary concern in Europe.

The 2000 World Health Report on health systems was controversial. This is perhaps inevitable, given that countries were ranked from highest to lowest performance. However, the media coverage and heated debate that followed had important consequences in terms of policy response. Measuring health system performance and publishing the results triggers action. By contrast, using data to drive political change to strengthen children’s health systems in Europe has barely begun. The potential for using measures of child health system performance as a stimulus for improvement is immediately apparent. Understanding and strengthening health systems for the young will require a sustained and concerted effort to focus specifically on the needs of children and young people. The work presented in this thesis is intended to make a small and early contribution towards this important goal.
2.3 Overview of the papers presented in this dissertation

The papers included in this thesis will focus on describing and analysing child health and children's health services and systems in the context of wider social and economic conditions in the UK and Europe. The conceptual framework for assessing health systems described in figure 5 provides a thematic structure for the data, analysis, and discussion presented in this thesis. The four themes: health status, non-health system determinants, health system context and design, and healthcare system performance are drawn together in the discussion to form a partial and preliminary assessment of child health systems in the UK and Europe.

Child health status

Data from papers I, II, and IV will explore UK and European child health trends, focusing on mortality, healthcare need, and wider determinants. The data from each paper will take a contrasting perspective: paper I will examine UK child health, paper II will take a Europe-wide perspective, while results from paper IV will focus on the UK in a European context, seeking a deeper explanation for why children die.

Non-health system determinants of child health

Results from papers II and IV will give an overview of child health in the UK and Europe, examining factors beyond healthcare and health system determinants, such as poverty, inequality, and other social determinants.

Child health system context, challenges, and health system delivery features

Results from papers I – IV will set out information on healthcare and health system challenges relating to current and evolving healthcare need. Descriptions and review evidence about healthcare delivery system structure and processes of care will be given from all four papers. Since the overall aim concerns population health gain through health systems and healthcare, the focus of these papers is on developing better systems for child health which will likely involve reconfiguring services across the interfaces between hospitals, primary care,
and public health. Although European countries face common challenges, the different ways they respond reflects their particular culture, histories, health system and organizational structures, financing systems, and professional roles. These variations provide opportunities to learn from each others’ experiences. Papers I and II will examine child health systems in a selection of European countries, providing a review of evidence around European child health systems. Paper III will review evidence for transitional services, an aspect of healthcare that is becoming increasingly important as the epidemiological transition towards chronic conditions proceeds. Paper IV will examine UK health system approaches to promoting child survival, seeking to elicit important differences between European countries’ health systems that can provide insights and lessons to help strengthen the UK health system for children.

**Child healthcare system performance**

Data from paper I will examine health service factors that may be responsible for outcomes in the UK, while paper II will focus on aspects of healthcare for first contact and chronic condition services in western European countries. Paper IV will attempt to address some of the questions that were asked by researchers, professionals, policy makers, and the public after papers I and II were published, investigating why the UK has a greater child and adolescent mortality problem compared with Europe, with a view to making recommendations to improve child survival.

**Discussion and Conclusions**

The research to be presented in this thesis was conceived with the intention of furthering knowledge and understanding and to help shape effective responses in policy and practice for improving the health of children and young people in Europe. The findings of this thesis will be discussed and analysed, forming broad conclusions and making recommendations for European child health system strengthening.
3. AIMS

The primary and overarching aims for the work in this thesis are:

- To improve knowledge about European child health, health services and systems.
- To generate useful knowledge for the purpose of helping to shape effective changes in policy and practice to strengthen health systems and improve children's health in Europe.

Specific aims of the work comprising this thesis include:

**Paper I**
To explore trends in UK child health and the quality of health services, lessons for the UK from other European countries, and highlight important policy points.

**Paper II**
To explore the state of child health and health services in western European countries, derive key lessons from different approaches to common challenges, and make recommendations for whole systems planning for European child health.

**Paper III**
To enhance policy-relevant knowledge about an important and neglected part of health services; the transition between child and adult health care.

**Paper IV**
To explore trends in UK and EU15+ country child and adolescent mortality, seek explanations for deterioration in UK health system performance, and make targeted and unifying recommendations for improving UK child survival.
4. MATERIALS AND METHODS

All papers presented in this thesis used population level measures of health status and health system performance, and primary and secondary research evidence concerning policies and practice for health system assessments and recommendations. Papers I, II, and IV used publicly available databases to obtain population level aggregate data to analyse health status and aspects of health system delivery. Public databases, organisation reports, and published research literature were used to obtain evidence on health status, and healthcare system performance such as quality of care. Quantitative data gathered and analysed included mortality rate trends, excess deaths, DALYs, and workforce census numbers and ratios, while qualitative descriptive and analytical data included case reports and country health system descriptions. The latter were derived from primary research conducted for a related project using questionnaires with clinical scenarios and questions on specific aspects of health system delivery. Respondents were expert informants in 10 European countries. Additional secondary research was conducted, analysing published research on health systems. Paper III used publicly available research literature search engines to search systematically for published papers with specified parameters concerning transition health services. Detailed descriptions of methods are included in the subsequent section.

Paper I
We analysed all-cause standardised mortality rates per 100,000 population, for 0-14 year old children, in EU15 countries (those belonging to the European Union, pre 2004). All mortality data were obtained from the WHO mortality database (updated 2010) (129). We calculated smoothed rates using three year moving averages, and showed mortality trends for each country.

Excess mortality rates were calculated by applying the mortality rate from the country with the lowest rate, to the population of each other country. For
example, post-neonatal excess deaths in the UK were estimated by applying the postneonatal death rate of a comparator country, to the number of live births in the UK, to get the expected number of deaths per year. This figure has been subtracted from the observed number of deaths in the UK to get the number of postneonatal excess deaths per year. The estimated number of excess deaths for 1-14 year olds from all causes in the UK was calculated by applying the average age-specific death rates (1-4 years, 5-9 years, 10-14 years) of the country of comparison to the UK's population numbers in these age groups, to get the expected number of deaths per year. This figure (sum of the age groups) was then subtracted from the observed number of deaths in 1-14 year olds in the UK per year to get the number of excess deaths for 1-14 year olds from all causes. Figures shown are based on 5-year averages.

Comprehensive literature searches were done for related work in progress during the writing of this paper, which provided evidence on health service configuration in EU15 countries. These literature searches obtained health system evidence from a selection of northern and western European countries, focusing particularly on aspects of the organisation of primary and secondary care, and structures and processes of care across primary-secondary care boundaries. Workforce data was obtained from publicly available websites including professional organisations and OECD.

**Paper II**

We used mortality data from the WHO mortality database (updated 2010), restricting our analysis to EU15 countries (pre-2004) to draw meaningful comparisons between nations with similarly structured health care systems and outcome measures (129). We reviewed published evidence on child healthcare systems in a selection of broadly comparable European countries. A brief review of evidence concerning wider determinants involved in causation and in devising solutions, was conducted. This paper builds on previous work completed on child health services in Europe and integrates findings of a related project on
children's health services and systems in Europe, undertaken by the European Observatory on Health Systems and Policies, and which was subsequently published (65). Comprehensive literature reviews were completed for these publications; search strategies differed for each topic area but included searching PubMed and relevant reports published by the WHO, UN, EU, OECD, and European professional societies. We contacted known European experts to identify works of national importance and for additional information where necessary. In addition, for this paper we reviewed selected aspects of child health services that may help to differentiate between countries that are doing well from those that are doing less well. The intention was to draw out learning points from countries with good outcomes, or from those that have made progress in, and assessed, health service reform. The definition of children and young people varies throughout Europe. Our definition is those aged 18 years and younger. However, due to constraints of data availability (i.e. 5-year age bands), some comparisons are restricted to children under 14 years. To compare EU-15 countries we focused on WHO child mortality data, given its reliability and availability. Other data sources included OECD expenditure data and unpublished European Paediatric Association survey data. Morbidity data, while desirable, are often unreliable given the limitations in data collection and coding systems between countries, and are frequently unavailable and inconsistent. Most of the comparisons provided were limited by available data; where specific examples are provided, they were selected from countries that have good outcomes, and from countries that have made progress in developing services and/or have analysed what they have done.

**Paper III**

A systematic literature search was conducted in July 2010, which aimed to identify studies that evaluated health outcomes following one or more interventions in the period of transition between paediatric and adult services for children with chronic disease, mental illness, or disability. Studies were only included if they involved a health service intervention during the period of transition from paediatric to adult care, if they evaluated changes in health
outcomes following this transfer and if outcomes were compared either between an intervention and control group or pre and post intervention in a single group. A wide age range was included (11 to 25 years) to allow for the variation in the age of transfer to adult care as, for example, those with learning disabilities often remain under paediatric care into young adulthood. Studies were excluded if they addressed only educational or vocational service transitions and outcomes, rather than health.

A search was conducted using Medline, HMIC, PsycINFO, and Embase, which identified 1,998 unduplicated papers. The search strategy combined four series of terms related to: paediatric and adult populations, continuity of healthcare and transition, indicators of evaluation, chronic illnesses and disabilities. A preliminary literature search had identified some chronic conditions about which there was existing literature concerning problems in transition, for example diabetes mellitus, juvenile idiopathic arthritis and cystic fibrosis, so terms specifically related to these were incorporated into the search strategy. Papers published in any language, but with an English title and abstract, were considered. Abstracts were screened by one reviewer and rejected if it was clear that the article did not report an evaluation of transitional care or if inclusion criteria were not met. The full text was obtained for 34 papers, of which nine met the inclusion criteria. Repeating the search strategy in CINAHL and IBSS yielded 451 items of which four met the inclusion criteria. Only one paper identified in this second stage had not been identified by the Medline search. A search of grey literature identified a number of policy and guidance documents, but no new primary research meriting inclusion. We followed the Cochrane handbook guidance supporting the use of a systematic, narrative approach when meta-analysis is inappropriate, and synthesised results by thematic analysis (130).

**Paper IV** We used data from the OECD for infant mortality and the World Health Organisation World Mortality Database (WMD) for 1 to 19 year olds to calculate centiles of child and adolescent mortality for a group of comparable
wealthy countries identified as appropriate comparators for UK mortality (131). These countries are the 15 countries of the European Union in 2004 (excluding the UK) together with Australia, Canada, and Norway, referred to as the EU15+. We used OECD data for infant mortality as this is available from routinely published data (as deaths per 1000 live births of both sexes), whereas comparative mortality for 1-19 year olds required calculation of mortality rates per 100,000 population from WHO raw data. For 1-19 year olds, we calculated total annual mortality rates from 1970 to 2010 for each country for 1-4, 5-9, 10-14 and 15-19 years. We then calculated smoothed 10th, 25th, 50th, 75th, and 90th centiles for each age-group 0-19 years from 1970 to 2010 for the EU15+ using Stata 13. Low centiles indicate mortality that is low compared with countries in higher centiles. Smoothing was done using 3 year moving averages. Centiles were calculated for both sexes together for 0-9 year olds (due to minimal sex differences under 10 years) and separately by sex for 10-19 year olds. The most recent OECD infant mortality dataset (accessed 12 December 2014) provided data for the UK and all EU15+ countries up to 2012. In the WMD, the latest dataset (deposited November 2014) only contains UK mortality up to 2010. Similarly many other EU15+ countries lack data deposited past 2010. Thus we calculated EU15+ centiles for infants to 2012 but other age-groups to 2010. Other data presented were secondary analyses of data published by UNICEF and OECD. Analysis and interpretations derive from systematic and non-systematic literature reviews conducted for this and related publications.

**Ethical considerations**

All papers presented in this thesis were based on analyses of publicly available data, or published papers and reports. There were no patient-level data used or clinical or public health interventions involved.
5. RESULTS

Results from the four papers supporting this thesis will be presented in this section according to the four themes set out in the conceptual framework for assessing health systems (figure 5). The four themes are: health status and health outcomes, non-health system determinants, health system context and design, and healthcare system performance.

5.1 Papers I, II, IV

Health status and health outcomes

High-level child health status and health outcomes are shown for EU 15 and EU15+ countries. Data include all-cause mortality trends for various subgroup age categories. Excess deaths rates and numbers are also given. Figure 6, from paper I, shows trends in mortality rates for 0-14 year old children from 1986 to the most recently available year, demonstrating that while all countries have improved child survival, there are notable differences between similar countries, and the UK all-cause mortality rate for children age 0-14 years is markedly higher than comparable European countries.

Figure 7 from paper II extends the range of years examined compared with figure 6 (note also the different y axis scale) and demonstrates similarly that child survival has improved greatly in recent decades in all European countries. Both figures show the UK’s mortality rate rise in relative position over a period of years, from approximately median among European countries in the early 1980s, to a notably higher mortality rate than other European countries by the early 2000s.
Figure 6. Trends in mortality rates, all causes, per 100,000, 0-14 years (3 year moving averages, directly standardised rates)
Source: WHO (129)

Figure 7. Trends in mortality rates, all causes, per 100,000, 0-14 years (3 year moving averages, directly standardised rates)
Source: WHO (129)
Differences between countries were explored further by examining trends in mortality rate by smaller sub-categories of age. Figure 8 showing all-cause mortality rate trends among 1-14 year old children demonstrates that differences between countries persist when infants are excluded from the calculation. However differences between countries are narrower, suggesting that infant mortality differentials between UK and Europe contribute a substantial proportion, though not all, of the differences shown in the mortality rate trends for 0-14 year old children (note the different y axis scale).

Figure 8. Trends in mortality rates, all causes, per 100,000, 1-14 years (3 year moving averages, directly standardised rates)

Source: WHO (129)

The contribution that infant mortality alone makes to the differences between countries is examined further, and shown in figures 9, 10, and 11 demonstrating overall infant mortality rate trends, (number of deaths in a year among children under 1 year, per 1000 live births), and trends in neonatal and post-neonatal
mortality rate (number of deaths in a year among children from live birth to 28 days of age, and from 28 days to 1 year, respectively, per 1000 live births). Again, note the different y axis scales. The UK infant, neonatal and post-neonatal mortality rate trends are higher than other European countries shown. The postneonatal mortality rate appears to contribute more than neonatal mortality to the UK's higher overall infant mortality. However, comparing infant mortality rates is known to be difficult, because some of the international variation in rates may be due to differences in birth registration practice regarding babies born prematurely. Euro-peristat has published infant mortality data applying a common cut-off point of 22 weeks gestation, and with these conditions the UK's infant mortality rate remains well above the Nordic countries (132).

Figure 9. Trends in infant mortality rates, all causes, per 1000 live births (3 year moving averages, directly standardised rates)

Source: WHO (129)
Figure 10. Trends in neonatal mortality rates, all causes, per 1000 live births (3 year moving averages, directly standardised rates)
Source: WHO (129)

Figure 11. Trends in post-neonatal mortality rates, all causes, per 1000 live births (3 year moving averages, directly standardised rates)
Source: WHO (129)
Mortality rate differences between the UK and EU15+ countries are explored further in paper IV. Figures 12 and 13 show UK all-cause mortality rate trends plotted with EU15+ median, 25th and 75th centiles, for age groups as shown.
Figure 12. UK mortality for infants, 1-4 and 5-9 year olds (both sexes) plotted against age-specific EU15+ mortality centiles for the same period

Source: OECD, WHO (133, 134)
Male 10-14 year mortality

Male 15-19 year mortality
Figure 13. UK mortality for 10-14 and 15-19 year olds for males and females plotted against age- and sex-specific EU15+ mortality centiles for the same period.
Source: WHO (134)
Figures 12 and 13, for 0-9 years and 10-19 year olds respectively, show UK mortality over the past 40 years plotted against EU15+ mortality centiles for the same period. Note that the y axis has a different scale for the infant mortality graph. These figures show that in 1970, UK mortality was below the 25th centile in all age-groups aside from infancy which was higher (50th centile), and 5-9 year olds which was lower and fell below the 10th centile. By 2010, the UK’s position had declined markedly in all age-groups. UK infant mortality was above the 90th centile in 2012, and on the 75th centile for young children 1-4 years. For 5-9 year olds and 10-19 year old males, UK mortality in 2010 was very close to the 50th centile. For 10-19 year old females, mortality in the UK was close to the 75th centile. Viner and Wolfe et al have previously shown that these differences are statistically significant; mortality in the UK declined significantly less than the EU15+ over the past 40 years (135).

Age distribution and causes of death in the UK and Europe were explored further in paper IV. More than 5000 children and young people between 0-19 years of age died in the UK in 2012. The majority of child deaths (60%) happened before one year of age and the next largest proportion happened in adolescence (18%), and the causes vary substantially between age groups (124).

**Infants:** Between 70 and 80% of infant deaths happen in the first month of life and nearly two-thirds of deaths are among babies who were born preterm (132). The risk of death from conditions which may be the consequences of preterm birth persists into later childhood (136). In 2010, preterm birth rates for the UK ranged from 7.0% to 7.2%, compared with 5.2% to 6.4% for Nordic countries. Low birth weight is a major risk factor for infant death, and deaths among babies who were born weighing less than 2500 g account for about three-quarters of neonatal deaths and two-thirds of infant deaths. The rates for countries of the UK were relatively high, ranging from 5.7% to 7% of babies born, while those for the Nordic countries ranged from 3.4% to 5.1% (132).
Causes of neonatal death are difficult to compare because of differences in the ways they are classified, but in general, the excess neonatal mortality in the UK is largely attributable to perinatal causes, and the excess postneonatal mortality, is attributable to perinatal and other causes. Rates of deaths attributable to congenital anomalies and injuries are similar in the UK and the rest of the EU15+ (135). After perinatal and congenital causes, the next most common causes of death in babies under 1 year old are injuries and poisoning, and infection, each responsible for just 2% of deaths (137). Although there are many unintentional and accidental causes of injury-related deaths, and murder of children is comparatively rare, 35% of child victims of murder are under one year old, and the likeliest perpetrators are the mother or father (138).

Finally, stillbirths are an important factor to consider in relation to deaths in the first year of life. Comparisons are difficult because of differences in the way terminations on the grounds of congenital anomaly are reported. Even so, after imposing a common cut off of 28 weeks of gestation, Euro-Peristat found that the stillbirth rates for the four nations of the UK, ranging from 3.4 to 3.8 per 1000 total births, were among the highest in Europe, while those for the Nordic countries ranged from 1.8 to 2.8 per 1000 (132). Many of the risk factors for stillbirth, preterm birth, low-birth weight, and infant death are shared, including social inequality and poverty (139).

After the first year of life, the most common causes of death in childhood are cancer, other non-communicable diseases (NCD), and external causes including injuries. More than half of deaths among adolescents are from external causes; the major modes are transport injuries, intentional and non-intentional injuries including suicide and violent deaths (129). Notably, deaths from intentional injury among young people have not decreased for thirty years (136).

The UK adolescent all-cause mortality rate is similar to the EU15+ 50th centile. However, examining mortality by Global Burden of Disease (GBD) categories reveals that NCD mortality among UK adolescents is higher, masked in the all-
cause figures by the UK’s relatively low injury mortality (135). Non-communicable diseases caused 57% of deaths among 1-24 year olds in 2008 and the disparity in NCD mortality rates between the UK and other EU15+ countries has widened over the past 40 years such that by 2008 it was in the highest quartile (140). Among NCD deaths, cancer mortality in the UK is slightly higher than EU15+ countries, supporting other evidence that survival from some cancers may be lower than in Northern European countries, and possibly that some tumours are at a later stage by the time children are diagnosed (141). Furthermore the UK has higher mortality rates from neuropsychiatric causes, endocrine, respiratory, and digestive disorders, although injury mortality rates have fallen less in the UK than other countries (135). While suicide rates in the UK have dropped since the late 1990s, they are still high compared with some other European countries, and intentional injury deaths account for over a third of all injury-related deaths (136). Mortality from communicable diseases is now extremely low in all wealthy countries, and here the UK is similar to the EU15+ median (135).

The scale of differences in mortality rates between countries is shown by calculating excess deaths compared with Sweden, (chosen because it has the lowest mortality rate). Excess deaths are shown in table 2, from paper II. If all countries in the EU15 countries could reduce their child mortality to that of Sweden, an estimated 6,000 excess deaths could have been prevented in 2010.
Table 2. Child mortality rates (0-14 year, all cause, 5 year average) and excess deaths per year (absolute number), compared with Sweden

<table>
<thead>
<tr>
<th>Country</th>
<th>Mortality (directly standardised rate)*</th>
<th>Yearly excess deaths compared with Sweden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sweden</td>
<td>29.27</td>
<td>0</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>26.5</td>
<td>0</td>
</tr>
<tr>
<td>Finland</td>
<td>30.27</td>
<td>9</td>
</tr>
<tr>
<td>Spain</td>
<td>37.4</td>
<td>545</td>
</tr>
<tr>
<td>Greece</td>
<td>37.86</td>
<td>135</td>
</tr>
<tr>
<td>Germany</td>
<td>37.88</td>
<td>815</td>
</tr>
<tr>
<td>Italy</td>
<td>38.07</td>
<td>683</td>
</tr>
<tr>
<td>France</td>
<td>38.25</td>
<td>962</td>
</tr>
<tr>
<td>Austria</td>
<td>39.09</td>
<td>106</td>
</tr>
<tr>
<td>Ireland</td>
<td>39.78</td>
<td>98</td>
</tr>
<tr>
<td>Netherlands</td>
<td>40.66</td>
<td>292</td>
</tr>
<tr>
<td>Portugal</td>
<td>40.73</td>
<td>176</td>
</tr>
<tr>
<td>Denmark</td>
<td>42.69</td>
<td>121</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>47.73</td>
<td>1951</td>
</tr>
<tr>
<td>Belgium</td>
<td>47.77</td>
<td>304</td>
</tr>
</tbody>
</table>

Source: World Health Organization 2012 (142)
What might be the reasons for excess child and adolescent mortality in the UK? The UK and other European countries face many common challenges in child health and in determinants of health and outcomes, but countries are adapting their health systems to meet those challenges in different ways. Examining, comparing, and contrasting different European approaches to Government priority-setting, health systems and organisation, and health care and public health, provides useful insights that help shape policy recommendations to improve UK and European child health (65). The next section presents evidence regarding differences in determinants of child health between countries.
5.2 Papers II and IV  
Non-health system determinants of health

Evidence is presented in this section demonstrating the importance of non-healthcare system determinants of child health, and policy differences between countries.

There are striking inequities in children’s life chances and health outcomes, as shown in the previous section. Variations in health result from a complex interaction of cultural, social, and economic forces, including differential risk exposure and access to high quality health care (143). Many aspects of child health are amenable to government policies, especially those that affect the distribution of resources, employment, housing, education, and health care. This section presents evidence regarding non-health system determinants and their relation to health.

There is a clear association between health status and a country’s wealth as measured by gross domestic product (GDP), which is likely to reflect access to resources and equity of distribution as shown in figure 14.

Thus, countries with higher spending on social protection for families generally have lower child death rates, as shown in figure 15.
Figure 14. Child mortality (1-14 years) related to country wealth as measured by gross domestic product

Source: WHO (142)

* Directly standardised mortality rate
** GDP=gross domestic product
*** r=correlation coefficient
**** EU Country Codes (for figure 14 and 15)
Figure 15. Child mortality (1-14 years) related to social spending on families

* Correlation coefficient
** EU Country Codes, as per fig. 14
Source: WHO, OECD (142, 144)

The extent of child poverty in Europe is not always realised. In Sweden, 1.3% of children live in deprivation, whereas in Portugal 27.4% of children live in households that cannot afford to eat three meals per day (145). Given the lag in availability of data, the current true situation is likely to be even worse because of the financial crisis. The aggregate figures also conceal that children from ethnic minority families are more likely to live in poverty. Europe’s largest minority population is the Roma, who continue to be subject to widespread discrimination in many parts of Europe, with child health outcomes such as pre-term birth, communicable disease incidence, and death often much worse than those in the majority population (146, 147). Others at particular risk are children in families of migrants who are sans papier (without official papers), who face additional discrimination in many countries. Failure to enact policies that
support disadvantaged children and their families particularly in their earliest years has long lasting consequences: missed opportunities to interrupt the accumulation of disadvantage through the life-course and arrest its transmission down the generations (148).

Children who live in poverty and deprivation are less likely to survive than their richer peers. A social gradient for survival affects infants and adolescents and continues through the life course (149). Children who live in countries with wide gaps between rich and poor people are more likely to die than their peers living in countries where wealth is more equitably shared. It is notable that the decline in infant mortality in the UK slowed less rapidly from around 1990 onwards (as shown in figure 12) coincident with rising income inequality in the UK. In 1999, 3.4 million children in the UK, just over 25%, lived in relative poverty; a situation that prompted a political pledge to end child poverty (27). Great progress was made in the following five years. The relative child poverty rate fell to 22%, while the absolute poverty rate fell too, from 26% to 14% over the same period (27). However since then, progress has stalled and reversed. Absolute child poverty is rising in the UK, and 35% of households with children do not have an income that is high enough to ensure an acceptable standard of living (150, 151). The rate of relative child poverty is back up again to levels last seen in 1999: 2013 data reports that 27% of children in the UK now live in relative poverty, and absolute child poverty is up to 31%; much higher than the population as a whole (152). Moreover, the UK remains in the upper range of income inequality among European countries (144). Pressures on families are increasing throughout Europe, and are likely to be exacerbated by ongoing economic problems and reduced public service funding. Among families receiving public services, there are increasing rates of alcohol and substance addictions, mental ill health, relationship difficulties, challenging behaviour in children, intimate partner violence and parent-child conflicts (22).

In the UK, poverty and deprivation disproportionately affect children and young people compared with other age groups (25). As shown in table 3, this is in
distinction to many other European countries, where poverty and social exclusion are more fairly shared between age groups. By contrast, in Britain, recent social spending cuts disproportionately affect families with children. A third of British households have children, but those families bear two-thirds of the burden of recent benefit cuts (153). Food poverty and hunger are growing problems in the UK, with increasing numbers of families reliant on foodbanks (154).

Table 3. Population at risk of poverty or social exclusion in European countries.

<table>
<thead>
<tr>
<th>Country</th>
<th>Population at risk of poverty or social exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total (%)</td>
</tr>
<tr>
<td>Austria</td>
<td>17</td>
</tr>
<tr>
<td>Denmark</td>
<td>19</td>
</tr>
<tr>
<td>Finland</td>
<td>18</td>
</tr>
<tr>
<td>France</td>
<td>19</td>
</tr>
<tr>
<td>Germany</td>
<td>20</td>
</tr>
<tr>
<td>Italy</td>
<td>28</td>
</tr>
<tr>
<td>Netherlands</td>
<td>16</td>
</tr>
<tr>
<td>Spain</td>
<td>27</td>
</tr>
<tr>
<td>Sweden</td>
<td>16</td>
</tr>
<tr>
<td><strong>UK</strong></td>
<td><strong>23</strong></td>
</tr>
</tbody>
</table>

Source: Adapted from UNICEF Innocenti (155).
Poverty and inequity lead to adverse health outcomes and a higher risk of death through a variety of indirect causal pathways. Babies born in poverty are more likely to be stillborn or die in infancy (132, 139). Babies who are born too early or who have low birth weights are at higher risk for infant death, and there is also a link to other risk factors such as age at motherhood. Babies with mothers aged under 20 years or in their forties have higher rates of infant death than those with mothers aged between 20 and 34 years. In the UK, over 5% of mothers of babies born in 2010 were under 20 years old, whereas in Sweden, 1.6% of mothers were under 20 years (132). Adverse health behaviours that are linked to low birth weight and preterm birth, such as poor antenatal care, substance abuse, poor nutrition in pregnancy, and smoking, are more common in less advantaged socio-economic groups (156-158). Smoking in pregnancy, for example, is associated with a 20 to 30% higher likelihood of stillbirth, a 40% higher rate of infant mortality and a 200% higher incidence of Sudden Infant Death Syndrome (SIDS) (159). Low birth weight rates are higher among teenage mothers, possibly because of competition for nutrients between the fetus and its mother who is also growing and developing (160). Breastfeeding, which can protect babies from infection and help prevent SIDS, is less common in more disadvantaged socio-economic groups (23). Adolescents and young people who grow up in disadvantageous conditions face higher risks of external injury, and are more likely to engage in excessive alcohol intake and other risk behaviours (46). Finally, there is evidence to suggest epigenetic effects of early disadvantage may add cumulative risk throughout the life course and may be transmitted to subsequent generations (161).
5.3 Papers I-IV

Child health system context, challenges, and delivery system design

Data is provided on the epidemiological transition in child health, and on determinants of health which lie within the remit of a health system. Evidence is given on aspects of diversity among European child health systems that may account for some of the differences in health outcomes between countries.

5.3.1. Health context and challenges for health system delivery

The main aims of health systems are to improve health, and ensure the greatest possible health equity between people. The epidemiological transition, away from acute infectious illness and towards chronic disease and long-term conditions has changed the mortality burden among children over recent decades. This is illustrated in figure 16, which shows the proportion of deaths among children in the UK, by cause in 1948, when the NHS was founded, and nearly six decades later, in 2006. Similarly, figure 17 from paper II shows that while the all-cause mortality rate has fallen in all European countries examined there has also been a concomitant change in the distribution of causes of childhood deaths. Specifically, deaths from infections and respiratory causes have declined while the proportion attributable to NCDs has risen. In 2009/10 the most frequent cause of deaths among 1-14 year olds in the European Union was injury and poisoning, followed by cancer, and “other", largely congenital anomalies and neurological disorders.
Figure 16. Causes of deaths in children 0-14 years in 1948 and 2006, UK

Source: WHO (142)
The causes of deaths among children in Europe are changing: Distribution of mortality in the EU15 (1-14 yr) by cause 1960-2009

Source: WHO (129)

Morbidity in children in this age group is also dominated by NCDs, accounting for 76% of disability-adjusted life years (DALYs) lost, as shown in figure 18 from paper II. Of these, the most common three causes are neuropsychiatric disorders (mainly depression), congenital abnormalities, and respiratory diseases (mainly asthma).
The data in figures 16, 17, and 18 demonstrate that the main causes of death among children are changing, and that childhood mortality and morbidity is dominated by non-communicable disease and injuries. This has important implications for health systems, demonstrating where efforts must be focused to achieve maximal health gain. European health systems have been slow to adapt to the changing patterns of childhood morbidity and mortality in the child population. For example, most country health systems are still heavily focused
on hospital services that were designed largely for inpatient admissions and acute illnesses with long convalescent periods. Although there is a broad consensus that many health services could shift from hospital to community-based delivery, thus improving access and responsiveness and reducing costs, most have yet to do so. However, these changes should not compromise the provision of highly specialized and acute emergency care. The challenge is to find innovative ways of addressing and reaching these complex and potentially competing goals. The following sections present examples of delivery system design, including organisation and processes of first contact and chronic condition care, selected from countries that have notably good outcomes, and/or have evaluated their reforms.
5.3.2. Health system delivery features: first contact, chronic care models, workforce, and transition care

The balance between access and expertise is key to delivering safe effective equitable first contact care, because one of the greatest challenges facing health professionals working with children is how to differentiate potentially serious illness from minor problems. European countries struggle with achieving an optimal balance between access and expertise. Problems of this primary-secondary care divide or community-hospital gap manifest in inefficient and sometimes suboptimal quality care, and frequently in poor care experience too. For example, between 17 and 57% of patients attending emergency departments (ED) have problems considered non-urgent or minor by the clinicians who see them, and which could potentially have been dealt with in primary care (163-167).

Access to the NHS in the UK is generally excellent and highly equitable compared with other countries (168). However perceived difficulties in accessing urgent services have led to a plurality of first access care services, though paediatric expertise is inconsistent and diagnostic resources limited, so some services do not have the resources to deliver safe urgent care for children (169). Many parents seek care directly in emergency departments, and indeed one in three children is now admitted to hospital in their first year of life; 67% are short stay admissions, and 39% of these are for minor infections that could have been managed elsewhere (119). Children represent about 25% of a British general practice population but around 40% of its workload, young children being particularly frequent users(170). Many senior general practitioners have accumulated extensive experience of paediatrics, but fewer trainees now do any paediatric training post (in some parts of the country 40%-50% compared with 60% in 1970 (67, 68, 171). Experience matters, especially in recognising rare but serious illnesses in children. The high mortality rate from some acute disorders suggests that there are also children who need acute specialist care but who fail
to obtain it sufficiently quickly (115). By contrast, many paediatricians in the UK report seeing increasing numbers of children with minor problems. A recent study suggests that 36% of referrals to paediatricians are potentially avoidable and this partly reflects lack of knowledge or confidence by general practitioners (172). Few trainee paediatricians spend any time in general practice, however, and many feel poorly prepared for dealing with children who have minor illnesses or the behavioural problems, family, and school difficulties often seen in hospital paediatric clinics (173).

General practitioner trainees in Britain may not get any paediatric exposure beyond their generic general practitioner training year. Hospital based staff however do not have the capacity or the most appropriate skills to deal with minor illness (119, 174-177). These gaps in skills, confidence, and capacity between primary and secondary care create services that are overwhelmed with minor illnesses and acute conditions. Therefore children with chronic problems too often have to make do with disjointed care fitted in around acute services (121, 178, 179). Families report unsatisfactory care experiences, such as multiple appointments in different locations on different days, and inadequate coordination and communication between professionals. Efforts to integrate care across primary and secondary services are hampered by organisational, managerial, governance, and financial constraints.

European examples show how services can be reorganised to support collaboration between professionals across organisational and professional boundaries. Integrated care, bridging the gaps between specialist and generalist care, or between hospital and community care is an important policy driver, though more focus has been on services for the frail elderly population than children and young people (180). A key lesson from Europe is that closer cooperation between services, as has been developed in Sweden and the Netherlands, does not arise spontaneously but requires supportive policies backed up by adequate funding. Models of care in a range of western European countries are described briefly below.
Sweden

In Sweden, first access and some outpatient care for children is provided by general practitioners trained in paediatrics working closely with paediatricians and children’s nurses in local health centres. Sweden also has developed “chains of care” based on agreements between providers, to counter fragmentation of services that impedes quality improvement (181). Chains of Care operate in a system which has multi-professional primary care and children’s centres in which GPs, paediatricians, and children’s nurses can work closely together. The system was developed as a response to concerns about fragmentation of care resulting from excessive de-centralisation of services whereby professionals worked in separate organisations. Difficulties experienced included weak incentives for collaboration, perceived challenges to existing power structures, and conflicting values among participants, especially physicians. Implementation was facilitated by involving patients as active participants, allowing sufficient time for change, developing supportive policy and financing instruments, and maintaining a strong focus on quality improvement as a motivating force (181).

Netherlands

The Netherlands has responded specifically to concerns about the interface between primary and secondary care by developing Transmural Care defined as collaborative, integrated care delivered by health professionals from within and outside hospitals, in mutual agreement and according to the patient’s needs. The Netherlands has a general practice system similar to that in the UK but operating within a transmural service may help to improve coordination between primary and specialist care (182). The Dutch system is designed to support, and is supported through education, shared guidelines, and innovative payment systems (183). Health professionals have explicit individual and shared responsibilities; specialist nurses, for example, deal with hospital admission and discharge planning. However, evaluations have shown mixed results, with persisting evidence of discontinuity between primary and secondary care, whilst organisational integration did not always lead to clinical and service integration (183). The model however, is evolving, with greater attention to the use of financial incentives.
France

In France there are incentives to register with a general practitioner, but parents can choose between office based paediatricians and general practitioners for young children, shifting to general practitioners later in childhood. Children with long term conditions typically attend a paediatrician who coordinates care with a network of professionals (184). The French system of coordinated care for patients with chronic conditions, *affections de longue durée* (ALD), covers 30 specified conditions and applies national standards. Although not specific for children, the ALD includes conditions that affect children such as asthma. Children with chronic conditions fulfilling enrolment criteria receive a personal treatment plan with a predetermined list of investigations and interventions that will be covered by health insurance. Enrolled children receive routine care for the specified condition from a specialist service (delivered by a paediatric pneumologist for example) although parents are entitled to choose any doctor in the case of an acute exacerbation. Coordinated planned care is achieved through multidisciplinary appointments in health centres or specialist institutes. However, this approach with its focus on only one specialist aspect of the child’s health and development, is seen as expensive and creates tensions between generalists and specialists.

UK

In the UK, some networks of integrated services for adults have been implemented with components of the Chronic Care Model including delivery redesign and professional decision support, as set out in National Service Frameworks (NSF) for chronic diseases, such as diabetes (185). These changes, together with the Quality and Outcomes Framework (QOF), a pay-for-performance system in general practice, may have improved care of adults (186). But despite numerous strategies and reports, and standards set out in a Children’s NSF, comprehensive chronic care services tailored for the specific needs of children have not been implemented nationwide, and the QOF contains almost no measures of care for children (103). A model of integrated services for children, the Team Around the Child (TAC) programme, links education and social services. However, this focuses on children with complex social and
educational needs only and there is a relative lack of health-sector input. An early evaluation suggested that the program was hampered by an overly bureaucratic process of assessment and coordination (187). A recent national report on children’s health includes specific outcome measures for the quality of care for children with chronic conditions (163). However, implementing a new system for monitoring will be concurrent with large-scale reorganisation of the English health service, with moves to decentralise services and increase the number of providers (188). The Swedish and Dutch experiences suggest that these changes may add substantial difficulties and challenges to improving the integration of services for children with chronic conditions.

**Italy**

The Italian system is for primary care and specialist paediatricians to deliver all children’s medical care. However, they work in different organisations and have communication and coordination problems across primary and secondary care boundaries, similarly to the UK. **Italian services for children with long-term health care needs are differentiated according to the type and complexity of care required, and differ widely across regions.** Networks of service providers foster integration across a continuum of care from primary care to highly specialised services, and include health and social care organisations. Services provided at home, through *Assistenza Domiciliare Pediatrica* (ADP), are a recent development. ADP focuses on specific chronic diseases such as cystic fibrosis, and aims to coordinate care between family and primary and specialised paediatricians, ensuring that as much care as possible is delivered at home.

**Germany**

In Germany, most children have a primary care or family paediatrician. German patients have traditionally had a choice of direct access to a general practitioner or specialist. Recently patients have been incentivised to see general practitioners first, although children retain direct access to paediatricians. In Germany, general paediatricians with an interest in a particular chronic disease provide care in offices or hospitals for children who need moderately specialised care, for example children with asthma and allergies. Pneumologists care for children with all forms of respiratory illness including infection, asthma, and
cystic fibrosis, by working in teams with nurses, dieticians, and physiotherapists. Coordinated multidisciplinary care is facilitated by funding packages of care with a single provider organisation rather than the usual fee for service model. Multidisciplinary teams working in Sozial pädiatrischen Zentren (SPZ) provide care for children with developmental disorders, epilepsy, behavioural disorders, learning difficulties, and some chromosomal abnormalities. SPZs are usually co-located with hospitals to facilitate transfer of acutely ill children. Specialised paediatricians coordinate care for children with complex or rare chronic illnesses, working in teams with general paediatricians, psychologists, dieticians, and therapists. Pathways are organised on an individual patient basis, and it is rare for children to have multiple appointments in different places and on different days. Teams of hospital paediatricians and nurses provide most out-of-hours care for children with chronic illnesses.
5.3.3. Workforce issues

There are striking differences between European countries in the organization of children’s (non-hospital) first-contact services. There are three main models, predominantly based on which kinds of doctors are responsible: GPs, primary care paediatricians, and combinations of both. However, comparisons are difficult because there do not appear to be any comprehensive or large randomised controlled trials comparing first-contact models for children and also because of the subtleties and complexities of definitions. For example, in many countries first contact care services do not provide a gatekeeping function and access to specialist paediatricians is unrestricted. Furthermore, while Sweden’s model could be defined as GP-delivered it differs substantially from that in the UK. GPs in Sweden are more likely to receive training in paediatrics (GPs are required to train either in paediatrics or gynaecology and obstetrics) and often work closely with paediatricians and children’s nurses who may be co-located in health centres. By contrast, the UK has a more segregated model with GPs who may not have received any specific training in paediatrics beyond that received as undergraduates, and who work separately from paediatricians. The potential consequences of inadequate paediatric training and supervision of child health clinicians in Europe are apparent from an enquiry into child deaths which highlighted failures in recognition and management of severe diseases (115, 189).

The challenges of providing first-contact care are exemplified by the case of childhood cancer. Prompt diagnosis is crucial but can be difficult because childhood cancer is so rare. Approximately 3-5 children in a typical health district (population 330,000) will be diagnosed with cancer per year, so the likelihood of a primary care doctor encountering a child with cancer is low (190). Primary care paediatricians who look after children only will be more likely to have experience of rare diseases, whereas a typical general practitioner for whom children represent a quarter of their patient population will encounter a child presenting with cancer once every 20 years. However, potentially, this could be balanced by general practitioners’ greater experience of cancer in
adults, from which lessons of timely diagnosis and its challenges may be transferrable.

Comparable European countries with varying child health outcomes have several features that differ from the UK, as shown in table 4. These differences in workforce and service organisation may help explain variations in outcomes.

### Table 4. Key aspects of children’s healthcare and workforce models in Europe

<table>
<thead>
<tr>
<th>First access model</th>
<th>General practice</th>
<th>Combined</th>
<th>Primary care paediatrics</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of children aged 0-14 per paediatrician (2008)</td>
<td>3928</td>
<td>2434</td>
<td>1668</td>
</tr>
<tr>
<td>Number of children 0-14 yr per primary care doctor (2006-2008)</td>
<td>266</td>
<td>341</td>
<td>112</td>
</tr>
<tr>
<td>Usual first contact professional</td>
<td>GP, or clinic nurse</td>
<td>GP or youth health worker</td>
<td>GP or paediatrician</td>
</tr>
<tr>
<td>Training of first contact professional</td>
<td>40% GPs have 6/12 or less hospital paediatrics, child health training other child health training in general practice</td>
<td>GPs not formally required to have postgraduate training in paediatrics</td>
<td>Post graduate training for GPs must contain paediatrics or gynaecology</td>
</tr>
</tbody>
</table>

Source: WHO, ISTAT, RCPCH (142, 191, 192)
Trainee primary care and specialist paediatricians in Europe follow a curriculum beginning with a three year “common trunk” emphasising primary care (193). All five countries shown in table 4 have substantially more doctors looking after children (per capita) than the UK, but there are also important organisational differences (142, 191, 192).

The most recent and comprehensive data on first-contact services and professionals, albeit limited, comes from the European Pediatric Association’s survey of 46 European countries (Fig 19).

![Figure 19. Diversity in primary care provision for children in Europe](image)

Source: European Paediatric Association survey of EU country child health professional leaders, unpublished (194)
This includes a variety of service models particularly for first contact acute care, an area already highlighted in terms of disparity of outcomes. Although there is broad agreement about the key competencies needed for those providing first-contact care, countries differ in their attempts to achieve the optimal balance between expertise and accessibility. Two thirds of the 27 EU countries provide 5 years of training for paediatricians, including those that work in primary care. There is a three-year general training period, the “common trunk”, and two further years for primary care, general hospital-based paediatrics, or sub-specialty work. The relative equivalence of each of the three branches is intended to ensure that primary care paediatricians are prepared for the diversity of clinical and social problems which they will encounter in future practice while specialist paediatricians receive sufficient training in rare and complex problems (195, 196). GPs usually train for at least three years with a minimal 6-month requirement both in hospital and in primary care (197). Although 13 European countries have extended training to four years or longer, there remains considerable variability in the length, content, examinations, and regulation of training between countries (198, 199). There are many constraints to the structure and content of training that are not related to education, such as EU working time limits and availability of training posts. There is insufficient analysis of data on training to know how closely these variations correlate with competencies and ultimately with child health outcomes attributable to health services provided by these professionals.

Increasingly, much routine and some specialist care for children is delivered by nurses. Thus, child care is led by nurses in Sweden’s Child Healthcare Centres, with GPs, paediatricians, psychologists, therapists, and dentists being called on when needed. In the UK and Netherlands, nurses provide community-based care for children with asthma. Nurse-led asthma care for children seems at least as effective as that delivered by a GP or paediatrician and may be less expensive (200-202). The rising prevalence of eczema has stimulated interest in developing nurse-led care, since the time for explaining and demonstrating treatment is an important part of management and outcomes are comparable whether delivered by nurse or specialist doctor (203, 204).
5.3.4. Care beyond working hours

Children can become acutely ill at any time of the day or night. Several European countries have instituted significant changes in how primary care services are provided outside conventional working hours. Reforms in Denmark, the Netherlands, and the United Kingdom led to more centralised systems with larger groups of GPs providing care (205). In Spain there are paediatricians in primary care, in a system of multidisciplinary clinics where paediatricians and GPs work closely together. Other countries are beginning to develop similar services. For example, the Italian system is evolving towards a more cooperative model. Nurse telephone triage for children in Netherlands seems to be as effective as for adults, as measured by return consultations, although outcome data are unreported (205). Evidence from Denmark suggests that a new model based on large GP cooperatives, with direct telephone access to GPs out-of-hours, led to fewer home visits and more telephone consultations, and an initial decline in costs of 16%. However, the effects were short-lived, with costs reverting to pre-reform levels over the subsequent 3 years. Patient satisfaction decreased from 68% prior to the changes to 51% immediately after, but within 3 years was 56%, perhaps reflecting better communication and different expectations regarding the new system. However, it is not clear how different models of after-hours care affect clinical outcomes in children (206). The challenges of providing out of hours first-contact care for children in the UK was brought into sharp focus after changes in the national employment contract for GPs in 2004. Rises in hospital emergency department attendances and short admissions among children around this time may be related to changes in out-of-hours provision, highlighting the crucial role that first-contact care plays and the consequent effects on the rest of the health service (119). EU regulations allow free movement of professionals between countries. Differences in training and registration of doctors became an urgent and high profile concern after an elderly patient’s death, but there were also implications for quality of care and training standards for doctors looking after children (207).
5.3.5. Making integrating care happen: evidence from general population healthcare

The care of chronic disorders among adults has been high on the policy agenda in many European countries for the last decade, exemplified by the widespread use of elements of the Chronic Care Model which incorporates elements of first contact and chronic care, and often includes other health system and social care services (185). The research informing chronic care has demonstrated that several factors are consistently associated with successful health care delivery for adults: shared practice, with common guidelines; conducive organisational arrangements, such as co-location; information sharing; supportive financial processes; administrative support; common training and education opportunities; and shared values with, and effective leadership by, respected individuals. Barriers and facilitators to integrated care for adults and elderly, based on a preliminary review of the literature, are summarised in box 3.
### Box 3. Key barriers to and facilitators for improving integrated care for children with chronic conditions

Source: Authors’ deliberations based on the available literature (180, 184, 208, 209)
By contrast with adults, integrated healthcare for children with chronic disorders have attracted little formal evaluation outside the United States where the Medical Home, a type of chronic care model, has been implemented and evaluated in some areas (71). However there is now a growing recognition in the UK and Europe that chronic or integrated care models, and transition care, require special attention.
5.3.6. Transition care

The transition between paediatric and adult care for young people with chronic conditions is often poorly managed, with consequences in adolescence and adult life. Adverse effects have been reported on health including worsening of glycaemic control in young people with diabetes mellitus, graft failure in transplant recipients, and poor health outcomes for survivors of paediatric cancers and cardiac surgery possibly related to increased loss to follow-up (210-213). Qualitative research with young adults has confirmed that many experience the transfer to adult care as disjointed, and find it difficult to adjust to the increased responsibility they have for their own care when using adult services (214-216). Calls for improved transitional care have come from the American Academy of Pediatrics, English Department of Health, and Royal College of Physicians of Edinburgh, as well as subspecialty groups for cystic fibrosis, spina bifida, inflammatory bowel disease, and mental health problems, amongst others (217-224). Despite the evident need for transitional services, a major review of children’s health services in the United Kingdom reports that transition, “long the cause of complaint and unhappiness”, is a “critical area” for service improvement, as existing abrupt transfers are failing to meet young people’s needs (174). A recent consensus statement by clinicians, patients and families on transition for survivors of paediatric transplantation highlighted existing inconsistencies and recommended changes to standardise service delivery (225). The most effective way to achieve a smooth transition has become a subject of considerable debate, as whatever solution is adopted will require a comprehensive programme that reflects and encourages the patient’s physical, psychological and social development, rather than merely providing a physical transfer from paediatric to adult care.

A range of approaches to improving the processes and structure of transitional care has been proposed but it is not yet clear how effective these may be in improving health outcomes and there is wide variation in provision both geographically and according to condition (140, 226). Previous literature reviews have been limited in that they identified predominantly descriptive
articles, highlighting the issues surrounding transition and programme development, but largely without examining evidence for impact (227-229).

The systematic literature search published in paper IV obtained ten papers that fit the inclusion criteria. The studies evaluated interventions in the transition between paediatric and adult care, but varied in terms of overall study design, in the number and age range of participants, and the types and durations of intervention and follow up. Analysis identified common themes of study design, intervention, and outcome. Eight studies attempted comparison between an intervention group and controls although in only four cases was a standard intervention vs control design used (230-237). In the other four studies the methods included: retrospective analysis of outcomes from centres with differing arrangements for transition, compared with a district where adolescents were transferred directly to routine adult care as a control (Kipps and Nakhla); use of population data from a recent multi-centre study as the control (Gholap); comparison of outcomes for those who had undertaken a certain numbers of steps of a transition programme prior to transfer, with those who completed fewer steps functioning as control (Craig) (231, 232, 236, 237). Two studies (Holmes-Walker and Vidal) did not use any comparison group, but measured outcomes of a single group of patients pre and post transfer (238, 239). Eight studies included patients at different stages of adolescence (within the range 16 to 20 years) at transfer, indicating flexibility in the boundaries between paediatric and adult services. Two studies transferred patients at 18 years. Little information was given on how age of transfer for individual patients was decided, nor was there subgroup analysis for different age groups within studies. Eight studies examined services for patients with diabetes mellitus, one for cystic fibrosis and one for organ transplant recipients. Most studies focused around the event of transfer, rather than the overall transition process, which should begin with preparation early in adolescence.
**Intervention types**

The studies reported a range of interventions, and the common elements identified are summarised in table 5. We classified interventions according to whether they were primarily focused on the patient, the staff or on improving service provision or access to care. Interventions targeted at patients were educational programmes and improved self-management; staffing interventions focused on named transition co-ordinators or joint clinics run by paediatric and adult specialist physicians; and changes to service delivery included separate young adult clinics, out of hours phone support, and enhanced follow-up.
Table 5. Interventions tested and their evidence for efficacy

<table>
<thead>
<tr>
<th>Category of study</th>
<th>Intervention</th>
<th>Rationale</th>
<th>Range of strategies</th>
</tr>
</thead>
</table>
| Patient aspects   | Disease specific education                             | Improve understanding and self-management                        | • One-to-one teaching  
|                   |                                                        |                                                                  | • Printed material  
|                   |                                                        |                                                                  | • Adolescent friendly websites  
|                   |                                                        |                                                                  | • Group and peer support sessions                                                  |
|                   | Generic education or skills training                   | Improve self-management, ability to navigate system, increase autonomy | • Internet-based skills teaching  
|                   |                                                        |                                                                  | • One-to-one teaching                                                             |
| Staff aspects     | Named transition coordinator                           | Improve continuity of care, ensure structure transition process, improve planning and preparation | • Single point of contact  
|                   |                                                        |                                                                  | • Attending each appointment                                                      |
|                   |                                                        |                                                                  | • Providing emotional support                                                     |
|                   |                                                        |                                                                  | • Administrative support                                                          |
|                   | Joint paediatric - adult clinics                       | Gradual smooth transition, improve continuity, improve information sharing | • Staff from paediatric and adult clinics attend appointments                     |
| Service aspects   | Separate young adult clinic                            | Improve age-appropriate surroundings and thereby engagement      | • Young adult clinics held on separate days from general clinics                   |
|                   | Out of hours phone support                             | Improve fit with young people’s schedules                        | • Telephone advice on management                                                 |
|                   | Enhanced follow-up                                    | To counter loss to follow-up in adolescence                      | • Telephone calls to encourage return to clinics                                  |

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th>Number of studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>Disease specific education</td>
<td>Improve understanding and self-management</td>
<td>5</td>
</tr>
<tr>
<td>aspects</td>
<td></td>
<td></td>
<td>4 (successful)</td>
</tr>
<tr>
<td>Generic</td>
<td>education or skills training</td>
<td>Improve self-management, ability to navigate system, increase autonomy</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2 (successful)</td>
</tr>
<tr>
<td>Staff aspects</td>
<td>Named transition coordinator</td>
<td>Improve continuity of care, ensure structure transition process, improve planning and preparation</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2 (successful)</td>
</tr>
<tr>
<td>Joint</td>
<td>paediatric - adult clinics</td>
<td>Gradual smooth transition, improve continuity, improve information sharing</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3 (successful)</td>
</tr>
<tr>
<td>Service</td>
<td>Separate young adult clinic</td>
<td>Improve age-appropriate surroundings and thereby engagement</td>
<td>4</td>
</tr>
<tr>
<td>aspects</td>
<td></td>
<td></td>
<td>3 (successful)</td>
</tr>
<tr>
<td>Out of hours</td>
<td>phone support</td>
<td>Improve fit with young people’s schedules</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(successful)</td>
</tr>
<tr>
<td>Enhanced</td>
<td>follow-up</td>
<td>To counter loss to follow-up in adolescence</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2 (successful)</td>
</tr>
</tbody>
</table>
Outcomes

The studies focused on health outcomes, rather than outcomes reflecting the holistic definition of transition as a “process which addresses the medical, psychosocial and vocational issues as young people move from child to adult centred services” (240). The health outcome measures used were appropriate for the diverse conditions studied. The majority of studies measured disease specific biochemical indicators, such as HbA1c or creatinine, and / or health service use, such as percentage of missed follow up appointments. Biochemical markers such as HbA1c are intermediate indicators of quality of care and are relatively easily measured. However, it is arguable whether using such measurements over relatively brief periods (generally only 12 months) is a valid indicator of long term health benefits. More robust outcome measures included hospital admissions for diabetic ketoacidosis or prevalence of diabetic complications (nephropathy, retinopathy, hypoglycaemia). None, however, involved long-term follow-up of morbidity or mortality.

Six studies, all involving diabetes mellitus, showed a statistically significant difference (p<0.05 or less) in health outcome following the intervention; in some cases the difference was significant for only one of several outcomes measured. Of these, two compared parameters pre and post intervention, one retrospective study compared an intervention group with recent multicentre study figures, and the largest study identified (1507 patients) analysed results from centres with differing arrangements for transition in place. Of the two controlled studies, the first one demonstrated statistically significant improvement in the intervention group’s HbA1c, both in comparison to their baseline (p<0.01) and to the control group (p<0.05 at one year) and better clinic attendance rates. Interestingly, three years later, HbA1c was similar in both groups, calling into question the programme’s long-term impact. The second controlled study demonstrated mixed results: a statistically significant improvement in glycaemic control only for those with poorest diabetic control (one third of the total) and a significantly lower rate of hypertension (p = 0.03) but not diabetic ketoacidosis or microalbuminuria.
Table 6. Interventions and outcome measures for programmes which produced significant improvements

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease specific education programme</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Generic education / skills training</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Transition co-ordinator</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Joint paediatric / adult clinic</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Separate young adult clinic</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Out of hours phone support</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Enhanced follow-up</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

Comparison

<table>
<thead>
<tr>
<th>Outcome measures used (✓ = statistically significant result, x = not significant, ? = statistical significance not stated)</th>
<th>Cadario, 2009</th>
<th>Gholap, 2006</th>
<th>Holmes-Walker, 2007</th>
<th>Lane, 2007</th>
<th>Nakhla, 2009</th>
<th>Vidal, 2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>HbA1c</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Acute complications (DKA, hypoglycaemia)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Rate of loss to follow up / clinic attendance rate</td>
<td>✓</td>
<td>?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Chronic complications (hypertension, nephropathy, retinopathy)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Self-management skills</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Disease specific knowledge</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Rate of screening for complications</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Diabetes-related quality of life score</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

* for the tertile with highest HbA1c; no significant difference for group as a whole
Table 7. Summary of the benefits from programmes which produced improvements

<table>
<thead>
<tr>
<th>Study:</th>
<th>Statistically significant benefits:</th>
<th>Other outcome measures:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cadario, 2009</td>
<td><strong>Comparison between intervention and control groups:</strong></td>
<td>- No significant difference in HbA1c at three years post transfer</td>
</tr>
<tr>
<td></td>
<td>- Intervention group had improvement in HbA1c immediately post transfer (7.9+-1.0% vs 9.1+-0.4%, p&lt;0.01) while control group had no significant change</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- At one year post transfer: intervention group had significant decrease in HbA1c compared to baseline (Δmean +/- SEM -0.5+-/-0.3%, p&lt;0.05) while control group had a statistically insignificant increase in HbA1c; overall, intervention group had lower HbA1c than control (8.9+/0.5% vs 7.8+/0.5%, p&lt;0.01)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Improved clinic attendance rate at 1 year post transfer in intervention vs control groups (80.0+-12.5% vs 57.0+/- 5.0%, p&lt;0.05)</td>
<td>- Statistical significance not stated for difference in clinic non-attendance rates (12% intervention group vs 24.6% multi-centre study)</td>
</tr>
<tr>
<td></td>
<td>- Improved self reported rates of foot examinations, microalbuminuria screening, HbA1c monitoring, eye assessment</td>
<td></td>
</tr>
<tr>
<td>Gholap, 2006</td>
<td><strong>Intervention group compared with recent figures from multi-centre study:</strong></td>
<td>- No significant differences in rates of hypertension or retinopathy</td>
</tr>
<tr>
<td></td>
<td>- Significantly lower HbA1c (8.4 vs 9.5%, p&lt;0.001)</td>
<td>- Statistical significance not stated for difference in clinic non-attendance rates (12% intervention group vs 24.6% multi-centre study)</td>
</tr>
<tr>
<td></td>
<td>- Significantly higher rates of blood pressure monitoring (100% vs 88%, p&lt;0.001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Significantly better screening rates for nephropathy (80% vs 56%, p&lt;0.01)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Significantly lower rates of microalbuminuria / proteinuria (5% vs 21%, p&lt;0.02)</td>
<td></td>
</tr>
<tr>
<td>Holmes-Walker, 2007</td>
<td><strong>Single group, compared with baseline:</strong></td>
<td>- No significant difference in HbA1c between intervention and control groups as a whole</td>
</tr>
<tr>
<td></td>
<td>- Significant fall in HbA1c (8.8+-1.9% vs 9.3+-2.17%, p&lt;0.001)</td>
<td>- No significant difference in rates of DKA, microalbuminuria or clinic attendance</td>
</tr>
<tr>
<td></td>
<td>- Significant reduction in DKA admissions (incidence density ratio 0.62, 95% confidence interval 0.39, 0.99, p&lt;0.05)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Significant reduction in length of stay of readmissions (R^2=0.46, p=0.02)</td>
<td></td>
</tr>
<tr>
<td>Lane, 2007</td>
<td><strong>Comparison between intervention and control groups:</strong></td>
<td>- No significant difference in HbA1c between intervention and control groups as a whole</td>
</tr>
<tr>
<td></td>
<td>- Greater fall in HbA1c in the tertile with highest starting HbA1c in intervention vs control groups (p&lt;0.05 stated: exact figures not given)</td>
<td>- No significant difference in rates of DKA, microalbuminuria or clinic attendance</td>
</tr>
<tr>
<td></td>
<td>- Significantly lower rate of hypertension (p&lt;0.03) in the intervention group</td>
<td></td>
</tr>
<tr>
<td>Nakhla, 2009</td>
<td><strong>Comparison between existing groups:</strong></td>
<td>- No significant difference in diabetes related quality of life score</td>
</tr>
<tr>
<td></td>
<td>- Improved continuity group were significantly less likely to be admitted to hospital for their diabetes in the 2 years after transfer (relative risk of 0.23 (95% confidence interval 0.05 – 0.79) for diabetes-related hospitalisation.)</td>
<td>- Increased proportion of rapid-acting insulins used (52% vs 23%, p&lt;0.001)</td>
</tr>
<tr>
<td>Vidal, 2004</td>
<td><strong>Single group, compared with baseline:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Improvement in HbA1c (8.5+-1.7% vs 7.4+-1.4%, p&lt;0.001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Decrease in hypoglycaemic episodes (0.39 vs 0.14 per year, p&lt;0.001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Increased proportion of patients able to self-adjust insulin doses (13% vs 48%, p&lt;0.001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Improved knowledge of diabetes management (DKQ2 scores 25/35 vs 29/35, p&lt;0.001)</td>
<td></td>
</tr>
</tbody>
</table>
5.4 Papers I, II, IV

Healthcare system performance

Data is provided on aspects of healthcare performance in European countries. Population-level aggregate data is presented on quality of care with regard to the “getting better” dimension of healthcare needs as shown in figure 5 on assessing health systems. Evidence on healthcare performance processes is also presented, obtained through reviews of published literature.

5.4.1. Quality of care: health outcomes

One measure of health systems’ effectiveness is the rate of deaths from conditions that are amenable to healthcare (112). Cause-specific mortality rates for diseases whose care relies heavily on first contact services, together with all-cause mortality rates, are given for a selection of European countries in table 8 and presented according to model of first contact care. Figures 20 and 21 show further detail on mortality from healthcare amenable causes. Table 8 also shows all-cause mortality and annual number of excess deaths in the UK, relative to each comparator country, for 1-14 year old children, and for babies in the postneonatal period. Neonatal deaths are omitted from this analysis because they relate more to maternity, obstetric, and newborn care. Although the incidence of many diseases is affected by socioeconomic conditions, deaths from the diseases cited here should be preventable by healthcare. If the UK health system performed as well as that of Sweden, the best performing country in our sample, as many as 1500 children 0-14 years might not die each year (table 8).
### Table 8. Comparison of five year average mortality in childhood in European countries, and excess deaths in the UK (with reference to comparator countries) according to method of first access to medical care, 2003-7

<table>
<thead>
<tr>
<th></th>
<th>General practice</th>
<th>Primary care paediatrics</th>
<th>Combined</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>UK</td>
<td>Netherlands</td>
<td>Italy</td>
</tr>
<tr>
<td><strong>Standardised cause specific mortality (per 100 000 children aged 0 to 14 years)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meningococcal disease</td>
<td>0.47</td>
<td>0.24</td>
<td>0.13</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>0.65</td>
<td>0.47</td>
<td>0.34</td>
</tr>
<tr>
<td>Asthma</td>
<td>0.27</td>
<td>0.07</td>
<td>0.01</td>
</tr>
<tr>
<td><strong>All cause mortality (aged 1-14 years)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deaths per 100 000</td>
<td>15.3</td>
<td>13.8</td>
<td>13.9</td>
</tr>
<tr>
<td>children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Annual No of excess</td>
<td>—</td>
<td>757</td>
<td>649</td>
</tr>
<tr>
<td>deaths in UK*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Post-neonatal mortality (28 days to 1 year)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deaths per 1000 live</td>
<td>1.6</td>
<td>1.0</td>
<td>1.1</td>
</tr>
<tr>
<td>births</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Annual No of excess</td>
<td>—</td>
<td>397</td>
<td>334</td>
</tr>
<tr>
<td>deaths in UK*</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: WHO (129)

* Shows how many fewer deaths occur in other countries (age adjusted) per year, compared with the UK.
Pneumonia is the most common serious bacterial infection in children seen in primary care settings, and one from which deaths in childhood should be avoidable (241). Yet death rates vary substantially within the European Union, from 0 to 34.7 per 100,000 (figure 20). It is possible that practice regarding attributing cause of death for coding purposes varies between countries, and also that death from pneumonia may be a final common event from an underlying cause such as complex neurodevelopmental disorders. These explanations are less likely to apply to asthma, another common illness, and one from which children ought not to die. Mortality from asthma, however, is also strikingly variable between countries, even after adjusting for incidence of wheeze (figure 21).

Figure 20. Mortality from pneumonia in 0-14 year old children in Europe

Source: WHO (129)

*= standardized death rate
Figure 21. Asthma mortality and incidence of wheeze among children in Europe (0-14 years)

Source: WHO, Anderson (129, 242)

* = standardized death rate
The observed differences in mortality from health-care amenable conditions between countries suggest that there is considerable scope for improving management and outcomes. These findings are supplemented by national reviews, conducted in the UK as a statutory process. Child death review panels bring specialists together to investigate every child death, aiming to identify and describe patterns and causes of child death, and recommend actions to prevent deaths. Annual reports are published, and the most recent report showed that approximately one in five deaths among children and young people in the UK, in the year ending 31 March 2013, was considered preventable through policy and practice changes in health services and the wider health system. The highest proportion of deaths with modifiable factors (nearly 30%) were among children aged between one month and one year old, and between 15 and 17 years old (113, 114). A recently published report reviewing deaths from asthma in the UK found that a key risk for children and young people was the failure, in both primary and secondary care, to recognise risk of adverse outcome, and that in 93% of deaths reviewed, routine care was inadequate (243).

Mortality however represents only the tip of the iceberg of disease, and is subject to several caveats if used as an indicator of quality of care for children. Other outcomes and processes of care can help to further identify where problems lie, and what might be done to improve care.
5.4.2. Quality of care: care outcomes and processes

Care outcomes and processes of care for children with long term conditions are important to consider in assessing healthcare quality, especially as these conditions are an increasingly important component of the burden of childhood disease, as is illustrated in figure 18. Research in several countries has shown that up to two-thirds of hospitalisations for asthma among children could be avoided with better preventive care, including asthma action plans, improved asthma education and a reduction of risk factors such as parental smoking (126, 127). In the UK for example, only 3% of children with asthma have written plans to prevent and manage exacerbation, so contact with the health service is often reactive (244). There are many preventable asthma admissions, and as shown previously, mortality from asthma in the UK is higher than in comparable European countries (129). Similarly, a national (UK) audit found that 82% of diabetic children had HbA1c concentrations above target levels, with nearly 9% of children having at least one episode of ketoacidosis in the past year and only 4% receiving care consistent with guidelines (125). Poor diabetic control in children leads to more and earlier morbidity. These examples of care processes concern common illnesses which should be managed well in a high functioning health system.

Table 9 shows some of the UK-specific findings and suggests ways in which quality of care could be improved.
### Table 9. Examples of means for improving quality and care experience while potentially reducing costs of children's healthcare in the UK

<table>
<thead>
<tr>
<th>Aim (example target)</th>
<th>Factors affecting performance &amp; evidence</th>
<th>Cost of avoidable event*</th>
<th>Effect on health service</th>
<th>Suggested solution</th>
</tr>
</thead>
</table>
| Improve detection of acute illness (prevent unnecessary admissions for minor illness in children under 1 year old) | *1 in 3 children under one year old admitted to hospital; 2/3 are short-stay emergency admissions, of those 40% are for minor illnesses  
*Perceived access difficulties  
*Insufficient training, skills or confidence among first-access staff  
*Perverse incentives, eg waiting time targets and payment-by-results system favouring admission | >£100m† | Acute care takes precedence over planned care, leaving insufficient capacity for optimal care of children with long term conditions | *Ensuring appropriate use of each service, by improving access to primary care staff with appropriate training in child health, especially out of hours  
*Improving primary care access to investigations and short-term observation facilities |
| Improve disease prevention | *Insufficient emphasis on primary and secondary prevention, especially in primary care where most children with asthma are managed  
*75% asthma admissions avoidable | ≥£7m‡ | Acute care precedence leaves insufficient capacity to manage children with chronic problems | *Ensure comprehensive pathways of care in place provided by multidisciplinary teams with appropriate incentives to improve quality of preventive care  
*Integrating primary-secondary care  
*Improved access to specialist advice  
*Improved primary care access to diagnostic tests |
| Improve planned care for children with chronic problems (prevent unnecessary paediatric outpatient referrals from primary care) | Insufficient training, skills, confidence or incentives to provide high quality comprehensive management of children's chronic disease in primary care | £360 000 saved out of every £1m spent on general paediatric outpatient appts§ | Paediatric outpatient service capacity limited by demands of acute care, workforce shortages – resources limited for children with serious or complex long term conditions | *Integrating primary-secondary care  
*Improved access to specialist advice  
*Improved primary care access to diagnostic tests |

Source: Asthma UK, Saxena, HM Government, Hospital Episode Statistics, WHO (118, 119, 245-247)

†Calculated by multiplying the number of hospital discharges for children under 1 year old in 2007 in England (603 029) by average non-elective tariff for minor admissions (£662), by 67.3% (proportion of short stay admissions), by 39% (proportion of short admissions caused by minor illness).

‡Calculated by multiplying the number of childhood asthma hospital discharges in England (excluding day cases) for 2009-10 (15 983) by 2010-11 tariff for short (0-3 days) non-elective spell (£648), by 75% (proportion thought to be avoidable). The average duration of admission for a child with asthma is 1.2 days. Calculation: 15 983x648=x.75=£7,767,738.

§Proportion of cost that is thought to be avoidable. Outpatient data are insufficiently reliable to use for calculating the actual cost. A new patient paediatric outpatient appointment costs £236.
Population level health status and outcomes data presented in this section demonstrate that child survival and child health outcomes have improved, but that there are important differences between countries. These variations reflect different approaches to meeting similar challenges, and therefore present opportunities for learning; a natural laboratory. Features of European child health systems were described using case studies and evidence reviews, and aspects of system and service performance data were presented.

The results presented will be analysed by themes, according to the framework illustrated in figure 5. Analyses of health status and outcomes, non health system determinants, health systems and delivery features, and healthcare systems will be drawn together into conclusions. Finally, recommendations will be suggested for strengthening child health systems in Europe.
6. DISCUSSION

6.1. Key findings

The results from the papers supporting this thesis were presented according to the health systems assessment framework themes shown in figure 5. The main findings are given here:

**Health status and health outcomes**

- Child survival has improved markedly across all European countries examined; some countries have improved considerably more than others.
- The UK has failed to match the mortality gains made in other EU countries over the past four decades.
- The scale of difference in child survival between EU countries is substantial, amounting to an estimated excess of 6,000 deaths in children under 15 years of age, per year.
- Most childhood deaths in the UK happen in infancy or adolescence, and the excess deaths between the UK and EU 15+ countries are mostly in these age groups; a subsequent paper showed that most of the differences are for all cause mortality among infants, and for NCDs among adolescents.

**Determinants of health – non-healthcare**

- There are inequities in survival between rich and poor children, and countries that spend more on social protection have lower child mortality rates.
- Children in the UK are more likely to be poor or living in social exclusion, compared with adults. Children in the UK, compared with other countries, are disproportionately disadvantaged relative to adults.

**Child health system – context, challenges, health system delivery features**

- The main causes of death among children have changed substantially over the past few decades.
- Non-communicable diseases contribute the majority of the burden of disease among children.
- European countries’ health systems face similar challenges, but attempt to balance access with expertise by adapting their first contact, chronic
care services, and supporting systems in different ways which can offer insights to others.

- There are three main types of first contact care model in Europe, which may be important in explaining different outcomes.
- Characteristics of health systems with good outcomes include flexible first contact and chronic care models which promote cooperation, and higher workforce to patient ratios. Achieving these qualities requires supportive organisational policies and practices.
- The existing evidence for effective transition care supports the use of education programmes, joint paediatric-adult clinics, and specific young adult clinics.

**Healthcare system performance: outcomes and processes**

- Mortality from diseases such as pneumonia and asthma that should be amenable to healthcare varies between countries.
- There is evidence for poor quality of healthcare processes for children with long term conditions in the UK and other countries.
6.2. Thematic analysis

All four papers featured in this thesis have addressed important topics in child health, and have contributed to changes in practice and policy in the UK. The unifying theme of these publications, together with the associated and subsequent work, is a population perspective on child health, focusing specifically on children’s health services and systems. Maximal population health gain should follow from directing attention and resources on the health needs of the majority of the child population, as originally described by Geoffrey Rose (248). Strengthening health systems to more effectively prevent and manage ordinary and everyday problems facing children and families across Europe should result in a shift in the normal distribution curve describing population health. Thus more children are brought into the healthy group, and fewer remain in the unhealthy group. The research presented in this thesis amounts to a partial and preliminary assessment of European child health systems. Three broad conclusions can be drawn.

- First, child survival and health in Europe are improving, but more in some countries than others. This is demonstrated by European country comparisons of mortality trends, excess deaths, determinants of health, and health service outcomes.
- Second, important determinants of child health which lie outside the bounds of a health system are amenable to economic and social policy, and action in these domains is essential in a comprehensive approach to strengthening health systems and improving health. Data showing associations between child mortality and country wealth, and between child mortality and social spending, together with case studies and evidence reviews exploring different country approaches to addressing problems they have in common, provide evidence that political decisions on economic and social policy are matters of life and death for children.
- Third, a whole systems approach is needed to strengthen health systems and improve health services. Healthcare amenable mortality rates,
healthcare outcomes and process measures, together with reviews of other published evidence underpin this final conclusion.

Each of these conclusions will be discussed in detail in the sections to follow.

**Child survival and health in Europe are improving, but more in some countries than others.**

All EU15 countries have had remarkable reductions in child mortality over recent decades. Papers I, II, and IV highlighted the variations in child mortality rates between comparable European countries and expressed these variations in terms of rates and excess deaths. Both Papers I and II presented high-level perspectives on UK and European child health system performance, revealing significant problems in the UK. Both papers explored contributory factors, and attempted to draw out lessons by examining European experiences in similar domains. These papers provoked a deal of media interest and concern among professionals, and significant interest among UK politicians (249). There were notably stormy reactions from some quarters. For example, the British Medical Association wrote to complain about newspaper headlines which claimed that paper II blamed GPs for the excess mortality in the UK compared with Sweden (250).

The concept of avoidable deaths in childhood provokes controversy and challenge. How would we go about defining what proportion of childhood deaths ought to be preventable? Sweden currently has the lowest child mortality rate in Europe. Excess deaths indicate the scale of difference between countries’ mortality rates, in a way that is meaningful to the public and politicians. Paper II showed that the UK has just under 2000 more deaths among children under 14 years old than it would do if it had the same mortality rate as in Sweden. But is Sweden’s mortality rate as low as is realistically achievable by any country? Crucially, is there any reason why the UK could not achieve at least the same mortality rate as Sweden?
Concern is growing in the UK that it lags behind in mortality and in health compared with similar countries. This was most recently reiterated in a paper published by Viner and Wolfe in 2014 which showed that the UK has failed to match the mortality gains made by the other EU15+ countries and analysed trends by age and cause (135). This paper showed that in 1970 UK total mortality for children and young people aged 1 – 24 years was in the best EU15+ quartile, but that by 2008 total mortality for infants, and children 1-4 years in the UK was in the worst quartile of EU15+ countries, with 1035 excess deaths in infants and 68 for 1-4 years. Trends for age groups between 5 and 24 years are more complex with less dramatic but nonetheless consistent differences between the UK and EU15+. A new finding was that all-cause mortality rates and trends mask significant problems in NCD mortality among UK children, adolescents, and young adults. NCD causes were responsible for 57% of deaths among 1-24 year olds in 2008. NCD mortality in 1970 in the UK for all age groups was approximately at the EU15+ mean. By 2000, NCD mortality in the UK had declined less quickly than in the EU15+ countries, and had drifted up to the worst quartile for all age groups. By 2008, there were 446 excess deaths from NCD causes per year in the UK compared with the EU15+ average.

Child survival in Europe is indeed improving, but there are notable differences between countries. The data underpinning this statement are population level all-cause mortality rate trends. This is a valid measure, and trends can reliably be compared between countries. Excess deaths give a meaningful description of the scale of difference between mortality rate differences. Moreover excess deaths indicate what is feasible to achieve; a goal to aspire to. However it is more challenging to determine what proportion of the UK, or any country's excess child and adolescent deaths is attributable to social determinants, health system factors, or healthcare. Since most deaths happen in the first year of life, when there is a strong association between social disadvantage and risk of death, it has been argued that social determinants explain most of the excess mortality in the UK, while it is also clear that micro-level healthcare-related causes provide an overly simplistic explanation for lay media seeking to explain country differences. There are no comprehensive assessments of European child health
system performance, so we cannot answer with precision the question why children are more likely to die in the UK than in some European countries. However we can identify where systems and practices vary notably between countries, and we can also identify deficits in policy and practice which are remediable.

**Important determinants of child health lie outside the bounds of a health system and are amenable to economic and social policy.**

From before birth, social determinants such as poverty and inequity and the policies that reinforce or mitigate their effects, influence children’s health, development, happiness, and future economic prosperity (251).

Approximately a quarter of all infant deaths in England and Wales would be prevented if all babies were born in circumstances as favourable as the least deprived families (252). Supportive family policy can help protect children from the damaging effects of poverty and inequality. Countries that spend more on social protection for families have lower child mortality rates (33, 253). Child survival in Britain and other countries with significant social and economic inequalities would be improved through macroeconomic policies to redistribute wealth and narrow the gap between rich and poor people. Social policies that protect children and families would also help ensure that children survive and thrive. More downstream policies designed to improve social determinants of health are sometimes translated into policies to modify health behaviours. These interventions need to go beyond merely providing information on healthy choices, since social disadvantage is often linked with poor self-esteem, lack of personal agency, and poor mental health. Improving negative health behaviours such as smoking and alcohol consumption requires a nuanced and evidenced approach to health policy. Making healthy choices the easy ones to make means implementing policies such as financial subsidies on fruit and vegetables and taxes on less healthy foods, plain packaging of tobacco, and minimum price per unit of alcohol (254-256). Finally, policies to improve social determinants must be targeted proportionately across the social gradient to reduce health inequalities (257).
Population level measures of mortality and country-level variables such as GDP and social spending are correlated, demonstrating the relation between dependent and independent variables. These data are valid and useful, though they are only correlations and do not necessarily indicate causation. Although the findings are not a surprise they are analysed and presented in new context as part of a European child health systems analysis. The findings are reinforced through other published evidence obtained through literature reviews. The secondary analysis of UNICEF data shown in table 3 highlights specific aspects of the data which had not been readily apparent previously: that UK economic and social policy disproportionately disadvantages children and young people.

**A whole systems approach is needed to strengthen health systems and improve health services.**

The diversity of child health determinants, as discussed in the background section of this thesis, and the complexity of health systems and policy discussed thereafter, make it clear that a whole systems approach is needed to promote and protect child health. Evidence for how that might be done will be discussed in the following sections.

**Rights and advocacy**

The United Nations Convention on the Rights of the Child offers a framework for policies to support child health and wellbeing, and the European Council has issued guidelines on child friendly health care (258, 259). Politicians and policymakers often appear reluctant however, to translate into policies the increasing evidence that the foundations of life-long health are built through greater investments in the early years and by adopting an approach to policy-making consistent with the goals of the UN CRC. A whole systems approach to improving child health will require action through all levels of policy and practice. Accountability is an important means of ensuring goal translation and progress (260).
Accountability

Accountability is important if the voices of children are to be heard effectively, and to ensure goal translation. Accountability can be strengthened through a framework of monitoring, reviewing, and remediing processes (261). National oversight mechanisms with responsibility for child health services and tasked with devising action plans to address problems when they arise could also help strengthen accountability. In paper IV, it was proposed that countries should identify a small number of context-relevant indicators for child health services and appoint a monitoring organisation with open and transparent responsibility for collecting and analysing data. A national child health oversight committee reporting to a minister of State responsible for child health could regularly review progress based on data, and implement remediing action. Such an accountability mechanism could be helpful for improving the conditions for child health from the most upstream determinants through health systems, public health interventions, and individual level healthcare.

Health system stewardship, financing, and organisation

High level features of health systems are important for ensuring accessible high quality care for children and young people. High level health systems comparisons across Europe can give indications for where and how improvements could be made. For example, the UK’s tax-funded nationalised health service delivers high quality outcomes for the general adult population and overall performs efficiently and well in high level indicators compared with many similar OECD and European countries (262). However, recent health system reforms in the UK seem to be producing increasing fragmentation of both commissioning (healthcare planning and purchasing) and provider functions, and accountability for the quality of children’s health care remains unclear. Sweden followed the UK’s example of market-based reforms in the 1980s, but - in response to increasing fragmentation of services - later reverted to a more cooperative model. For example, extensive decentralisation in Sweden was partially reversed with the formation of elected regional health authorities, while county-level taxes for funding a high proportion of health sector costs were intended to enhance system responsiveness (263). Thus Sweden and the UK
offered each other opportunities for learning from the impacts of health policy implementation. Effective policy comparison requires reliable data, and a framework for interpreting context and defining the boundaries of the system, is described in the background section of this thesis. Although there is published evidence on health system stewardship, financing, and organisation for the whole population, these focus more on low and middle income countries, and their applicability for children and for European health systems is unclear.

**A population-based approach to planning, delivery, and evaluation**

Successful improvements in children’s health and social care is dependent on valid measures of health and social care needs and system performance. Country differences in approach to data collection and sharing may help to explain differences in their abilities to plan and implement population-based care, and strengthen health systems. For example, Sweden’s system of national data registries strongly supports the ability to deliver health and care services tailored to need. Universal data collection and widespread data sharing is a point of national pride, and enable health service improvements and research that are likely to be important elements contributing to Sweden’s leading position in many of the European league tables of health system performance. By contrast, in England, data sharing is less well developed, but may be more complex because of the plurality of providers of healthcare who compete with each other for business. The UK, however has led the way in developing child death reviews, which are now statutory in England and which offer a means of learning from deaths and taking action to prevent further deaths (113, 264). Sweden’s systems for planning and organising child health services is further strengthened by involving child health specialists to help ensure a child-centric model of care. Furthermore, at a micro level, “chains of care” backed by financial incentives were developed specifically to improve integration and encourage cooperation between professionals and providers and seem to contribute to a successful model of care (181).
**Public health interventions and social policies**

Policies and interventions outside the health system have the potential to improve health and reduce inequities, and accumulate advantages for individuals and populations throughout the life-course (265). In public health and social policy there are useful examples of learning through policy analysis and country comparison.

Public health interventions that directly or indirectly reduce risk factors and causes of child mortality include interventions to reduce or prevent smoking, alcohol consumption, and injuries that are either non-intentional or related to maltreatment. Smoking often begins in adolescence, so policies and practice targeting young people are important. Compared with some other countries, the UK scores highly on implementation of tobacco control policies. However specifically for children, young people, and women who are pregnant or expecting to be, there are further actions that could be taken, such as standardised packaging of tobacco (255, 266). Alcohol consumption among young people in the UK is a considerable public health concern, with signs of alcohol-related liver disease affecting people at increasingly younger adult ages (267, 268). There is good evidence that minimum pricing of alcohol is effective at reducing consumption, and there are further alcohol-related harm reduction strategies that can be implemented (254, 256). There are effective interventions to prevent most common causes of death from injuries, however legislation, policy implementation, and enforcement are crucial (269). Given the lack of progress in reducing violence-related deaths and injuries among children and young people in the UK, an effective policy response is needed urgently. There are many other specific measures that can be taken to protect children. This is demonstrated by data on mortality from injuries and violence published by Armour-Marshall and Wolfe showing that while external causes of death are much more common among children in poorer families and in poorer countries, Northern European countries, such as Sweden and the Netherlands, have achieved sustained reductions in child deaths from road traffic injuries. Both countries introduced legislation and measures directed at reducing traffic speed,
separating vehicles from other road users, and mandating safety equipment such as child restraints (269, 270). A further useful example of policy-mediated child health improvement, is France’s reduction of childhood drowning through pool safety legislation (271).

Social protection for the earliest years of life and the most vulnerable and disadvantaged children is important to reduce the likelihood that children’s health and wellbeing will suffer, particularly important during the ongoing, most severe financial crisis for decades (272). Providing universal access to high quality affordable early years education is a key strategy for reducing social inequalities. However, this is still only an aspiration for disadvantaged children in many countries, especially those in marginalized groups such as Roma and migrants without official papers. The England and Wales Children Act 1989 (section 17) places a duty on local authorities to provide services to children in need of additional support beyond universally available care (273). The intention is to ensure that children achieve a reasonable standard of wellbeing or their health or development is not significantly impaired. However increasing demand and reduced funding puts pressure on social workers, which can result in rapid turnover of staff, such that there is a risk that professionals working in social work and safeguarding roles are inexperienced or inadequately supported. Social protection for vulnerable children is a vital part of ensuring that they reach their best attainable level of health. The UN CRC should serve to remind us that social and economic policies are part of life-saving and life-enhancing medicine for children, and an essential part of a whole systems plan for health.
Healthcare delivery systems

Healthcare systems are multifaceted. This thesis presents data on aspects including primary and first contact care, planned services, integrated care, transition, and workforce. In each regard there are potentially useful lessons to be learned through examining the diversity of approaches among European countries. The analyses in papers I and II suggest that comprehensive integrated teams in primary care settings should be able effectively to provide the majority of children’s healthcare. These findings are based on analyses of case studies and evidence reviews, and serve both to generate hypotheses and to suggest possible solutions to explore.

An important advantage in the UK compared with some other countries, is an equitable and accessible system of universal primary care, since countries with strong primary care systems deliver high quality outcomes (274). However much less is known about exactly how best to organise everyday healthcare in the interests of children and young people. There are no comprehensive reports on the quality of primary care for children in the UK, though there are some reports signalling concern in this area (275). As regards hospital care, the Healthcare Commission in the UK reports that 46% of hospitals are weak in paediatric outpatient care, with services designed around acute illness rather than chronic disease (121). While the explanation for country differences is not yet clear, there are measures that would be likely to improve the quality of care for children and young people in the UK and other countries.

A major challenge for all countries is ensuring optimal balance between expertise and access in primary care for children, and that workforce is appropriately skilled and resourced. Integrated care, variously defined as a means of ensuring strong cooperation between providers and sectors, is seen as an important mechanism for services to become more responsive to evolving health needs. Primary care and the structures and processes that foster integration are the foundation of a strong children’s health service. Integration can be described in at least two broad dimensions: horizontally (between health,
education, and social care) and vertically (between primary and secondary care). Information systems that enable coherent health service planning and foster cooperation between institutions and individuals are critical to the delivery of high quality care. Everyday healthcare is required by all children, some of the time. The majority of children are well most of the time, so health promotion and disease prevention are core parts of everyday healthcare. All children will get occasional acute illnesses, which can be minor or serious. The key to providing safe effective care for urgent need is to ensure the appropriate balance of access to services, and expertise of care. Cooperative team-based working in primary care settings should enable rapid on-site access to more specialist opinions, thus providing a more convenient service for patients and an effective diagnostic safety net (276).

A strong primary care service is essential for children and families. When primary care has a strong gate keeping role, the first contact care function is crucial to enable the rest of the health service to function effectively and efficiently. The observed variation in outcomes of childhood conditions and appropriateness of emergency contacts and admissions in some countries such as the UK, indicates potential to learn from others’ experiences. Sweden’s flexible model of first contact care may offer valuable lessons, given that Sweden has achieved some of the best outcomes for children in Europe. The Italian system, where primary care paediatricians provide most primary care for children, offers a useful contrast as a service that also provides high quality outcomes. Although paediatric specialists working in primary care are more expensive to train than GPs, and there may still be barriers between primary and secondary care, these problems may be balanced by better outcomes. In the UK many GPs lack significant post-graduate training in paediatrics, and deliver first-contact care separately from paediatricians. Although the strengths of this model have been celebrated, assessments usually relate to adults. Since there is some evidence of sub-optimal outcomes for children in the UK, it is therefore worth exploring more flexible approaches to primary care, that still preserve the best qualities of the family medicine system (274).
European evidence derived from case studies and reviews of published evidence suggests possible ways forward for the UK. For example, child health teams could comprise jointly trained general practitioners and paediatricians working with children’s nurses, health visitors, allied health professionals, and mental health professionals. This would require more doctors with paediatric training. General practitioners in the UK could have mandatory dedicated training in paediatrics, including management of acute illness and long term conditions, as they do in other countries. Training of paediatricians in the UK could include more health promotion, behavioural paediatrics, and management of long term conditions out of hospital. Furthermore European examples show how services can be reorganised to support collaboration between professionals across organisational and professional boundaries. Countries with strong primary care systems which also enable close cooperation between well trained adequately staffed health professional teams seem to be making progress in delivering high quality care (65, 253). There are several factors which facilitate cooperation, including financial incentives for team working and co-location, for example in the Netherlands and Sweden. The Swedish multiprofessional health centres and chains of care system and the Dutch transmural care models offer examples of how integrated services can address the fragmentation that currently impairs the efficiency and quality of children’s services in the UK. Workforce numbers, training, and team working are also important; Sweden has more doctors per child than the UK, and GPs in Sweden are required to be trained specifically in paediatrics and work in teams with children’s nurses and doctors (277).

Given the growing numbers of children and young people with chronic conditions in Europe, a major priority is developing comprehensive chronic care models which can achieve a shift in care away from a hospital-centric model towards a strong community-based primary care service that can effectively prevent illness and manage children and young people with chronic conditions, as well as acute minor illnesses. Children with chronic care needs should have coordinated comprehensive proactive care that is convenient and high quality. Integrated teams could fill the gap between primary and secondary care by providing high quality urgent care for minor illnesses. This should help prevent
unnecessary referrals and admissions, and improve the detection of potentially serious illness. This will, however, represent a substantial change to the current hospital-centric model, to one in which primary and secondary care providers work together rather than in separate silos as is the case in some countries. This would require commitment from bodies representing paediatricians, general practitioners, and other health professionals working in primary care, at national and European levels. These changes can build upon lessons learned in Sweden, the Netherlands, and the UK, for example. Ensuring continuity and consistency of care across the health system is crucial for both quality of life for children and their families, and for achieving better outcomes.

Cooperative integrated healthcare teams are likely to stand the best chance of delivering the right care, at the right time, in the right place, and by the right people. A renewed focus on primary care, delivered by a team of professionals that achieves an optimal balance between access and expertise for physical and mental health, social care, and other specialties, should enable the majority of children’s urgent and scheduled health needs to be managed in community settings (65, 275, 278, 279). First contact teams integrating generalists and specialists should be able to provide convenient high quality planned care for children and young people with long term conditions, as well as health promotion, disease prevention, and health education. Integrated services should be carefully coordinated with other providers in care networks, and work seamlessly with adults’ services so that young people can transition smoothly and effectively into the adult health care world. Such a comprehensive strong model of care, backed by wider policy actions to reduce risk and enhance resilience and quality of life, would help improve prevention and care of long-term conditions in children and young people.

There is limited evidence about how most effectively to structure and deliver transition care. However, there is increasing evidence as shown in paper III that joint paediatric-adult clinics, and specific young adult services can be helpful, and that transition coordinators can offer useful support to young people. These
services may be helpful in guiding health service planning towards the goal of improving services and health outcomes for young people with chronic conditions.

All the countries examined in paper I have more doctors looking after children than in the UK; some have general practitioners with postgraduate training in paediatrics, many working closely with paediatricians. However, there is a need to reassess the training of all members of teams caring for children, ensuring that it supports new models of interprofessional care that bridge the primary-secondary care interface and focus on the needs of children (280-282). Professionals working with children need to progress beyond occasional discussion of referrals to collaboration on effective service development and professional training. The UK, which has a strong gate-keeping role between primary and secondary care could achieve this by enhancing specialist skills of general practitioners and generalist skills for paediatricians, with common curricula and flexible training and accreditation systems. The European Union provides for free movement of health professionals, based on the principle of mutual recognition of qualifications whereby each country must conform to very basic criteria for the training required. However, training standards are primarily based on the duration of learning rather than on its content. Although there are assessments of competence, there is a clear need to define transferrable standards for competencies of child health professionals, particularly those working in first-contact care where services and outcomes are variable. Many European professional organisations have sought ways of developing shared curricula and approaches to learning. However, progress has been limited in several countries because of deep divisions between professional groups, in some cases backed up by legal constraints or encouraged by inappropriate financial incentives. These issues will come to the fore since the trend for task-shifting from doctors to nurses is likely to continue. There is considerable scope for children's health professionals to share best practice if they can find ways to overcome these structural and cultural barriers.
6.3 Strengths and limitations

The research presented in this thesis amounts to a preliminary and partial assessment of child health systems in Europe, on which is based a set of recommendations for strengthening child health systems. This has not, to my knowledge, been attempted before. Therefore to embark on research in a previously neglected aspect of UK and European child health can be considered a strong point of the work. Being a relatively new field, and addressing itself to important topics, this work has been successful in capturing policy-makers attention. There are early signs of impact on policy in the UK, and further research has been stimulated in the UK and other European countries.

Just as the WHO health systems report published in 2000 was controversial and received with scepticism by some, and yet triggered action among policy makers in many countries, papers I and II produced similar consequences in the UK. The results were highlighted in several government associated reports, such as the national Children and Young People’s Outcomes Forum annual reports and the Chief Medical Officer for England’s annual report, and helped trigger the Department of Health’s task group on avoidable mortality (104, 163, 283). The Royal College of Paediatrics and Child Health and National Children’s Bureau noted the interest and commissioned a report to explore the topics introduced in papers I and II, and to make targeted recommendations for each of the four devolved nations of the UK. The report was called “Why Children Die” and it also attracted a deal of press and political interest. Debates were held in the UK and Scottish parliaments, and the Welsh, and Northern Irish assemblies. Paper IV was commissioned when the Why Children Die report was published, and builds on the findings and recommendations made in earlier publications. A Countdown for UK child survival initiative was proposed in paper IV, which now has the support of a wide variety of statutory, professional, and voluntary bodies.

Inevitably, the weaknesses of the research comprising this thesis are closely bound up with its strengths. Weaknesses fall into two broad areas: scope and methods.
Scope
As a comprehensive assessment of European child health systems, the research presented in this thesis is incomplete, and its preliminary and partial nature is acknowledged. Based on the discovery that UK child mortality was notably higher than other countries, the original intentions behind the research were to explore differences in child health between European countries with a view to understanding why the UK performed so poorly. Health services, systems, and wider social and economic determinants of child health were investigated, and together the results amount to a partial assessment of health systems. Starting with health status, the first tier in figure 5, mortality and health conditions were investigated, but quality of life, wellbeing, and life expectancy were not. For the second tier, some non-healthcare determinants were investigated, in particular social and economic conditions, but others such as physical environment were not. Healthcare system delivery features and performance were investigated, but only as regards primary and secondary care and relatedly, integrated care and transitional care, as these are the fundamental parts of everyday healthcare and so contribute most towards population health gain through healthcare. This distinction fits the public health ethos in child population medicine. Financing, resource generation, and health system governance were not covered. In terms of healthcare needs, reactive healthcare was investigated, but not preventive, nor palliative. Effectiveness was included, but there is limited data available, and safety and access were included only in as much as they relate to effectiveness. Cost and responsiveness were not assessed.

Methods
This thesis has several limitations relating to the methods available for child health systems research, which bear upon the strength of the findings presented and the recommendations from which they are derived.

Papers I, II, and IV attempt to measure health status through various means. The purpose of measuring health status is both as an indication of healthcare need,
and also as an outcome of care. There are no comprehensive measures of health need and quality reflecting outcome of health service or system function, so available direct and indirect evidence is presented.

Mortality data are presented in papers I, II, and IV. Mortality gives a high level indication of health system performance, and helps indicate where attention should be directed. A clear benefit is that mortality data is routinely collected, and is readily accessible. All-cause mortality data in high-income countries is reliable and valid as a high level performance indicator. However all-cause mortality rates as an indicator of health service quality are not specific enough since healthcare is one of many determinants of survival. Examining mortality rates from causes amenable to healthcare gets closer to assessing healthcare quality, but raises other questions for example about the comparability of coding practice between countries. Death certification practice, which forms the foundation for routine mortality data, is variable. Excess deaths are a helpful way of communicating information about mortality rates meaningfully at the individual level. Politically effective advocacy messages are readily shaped around excess death data. However, comparisons between countries can become simplistic and misleading, as was seen in the response to paper I, for example. Audit data of selected cases of child death are referenced in papers I, II, and IV. This method is helpful for drawing attention to factors that could be improved, but comparisons between organisations, systems, or countries would not be reliable as uniform methods for child death review are not yet established. Moreover audit data can not reliably attribute causation at a population level.

Morbidity and risk factor data such as disease prevalence rates and trends and DALYs are useful in describing health need, but limited because there are few sources of routinely and regularly collected data. Risk factor data such as obesity trends are more widely available, as are health behaviour data though these are derived from questionnaires and are subject to biases.

Paper III is limited in the strength of conclusions it draws by the quality of methods used in the papers which constitute the review. The reviewed papers
relied on uncontrolled study designs or small non-randomised controlled samples, and complex interventions. Moreover, the studies were on limited population groups, and mostly restricted to service interventions for young people with diabetes mellitus. None of the studies measured long term health outcomes, instead identifying intermediate or proxy indicators. There were few high quality studies available, therefore the conclusions reached are limited. However, the paper has been frequently cited in other publications and reports, so the findings have added value to the current body of knowledge on transitional services and helped to identify future research priorities.

Indicators of health system functioning and specifically of healthcare quality are currently limited in child health. Health improvement through healthcare was considered in this dissertation, using high level measures of system performance. These results showed that all countries examined had improved, but some more than others. It is more difficult to arrive at a wholly satisfactory explanation for the differences between countries. However, differences between countries were explored as possible explanatory variables, and as potential policy and practice solutions for other countries. Case studies and evidence reviews form the basis for this evidence. In this aspect, child health systems research must rely on best available evidence and child health systems researchers must join in efforts to define new research methods and standards for evaluating evidence. Turning to the four elements of health services described: availability, accessibility, affordability, and quality, only quality was considered in depth in the papers presented in this dissertation. Quality measures, as has been discussed, are currently insufficiently comprehensive and are unable to provide rigorous cross-country comparisons. Thus quality measures were used indirectly, indicating areas of concern from which countries may benefit through quality improvement measures and by examining other ways of structuring systems and delivering services.

Throughout this thesis, it is acknowledged that more work must be done to improve health systems data availability and comparability in order to help us understand how well systems work, and what should be done differently to
improve health system performance for children. All four papers have used the best available health systems data, using these to draw cautious conclusions, and make practical constructive recommendations. The work presented in this dissertation has made substantial contributions to the early stages of child health systems research, and has helped shape child health policy in the UK.
6.4. Summary and recommendations

A preliminary and partial assessment of UK and other European health systems has been presented showing that health status and outcomes among children in Europe have improved considerably in recent decades. Substantial variability between countries in high level outcomes such as mortality suggests that there is scope for improvement. Social determinants of health are amenable to policy, and some countries have done more than others in devising and implementing policies to promote child survival. The main causes of death among children are changing as the epidemiological transition progresses, and health systems need to adapt. Healthcare amenable mortality for selected conditions is variable between countries, and there is evidence suggesting poor quality healthcare processes and outcomes in the UK, suggesting scope for improvement.

Although some successes in the improvement of child health in Europe have been noted, there is much work to be done. Changes in practice are contingent on supportive planning and policy, suggesting that a whole-systems approach is needed. The problems that need particular action can be described as a 3x3 plan, as illustrated in figure 22 from paper II. There are three general themes and three specific actions. A chronic care model is important, in view of the epidemiological transition. Developing such a model will require a change from the current dominant hospital-centric model of care, and there are examples of successes described in this thesis. First contact care is the foundation for health services, and an effective balance between access and expertise is essential. Flexible models of care and workforce seem to produce higher quality outcomes, though the evidence is preliminary. Child-specific health service and system outcome measures are important to develop for research and improving health systems. Child health systems research capacity needs to be built, as there are many unanswered questions regarding child health and health systems in Europe. Individual countries and EU-wide research bodies need to invest in health systems research for children. Finally, evidence must be translated to policy, and action should be assured through an effective accountability
mechanism. All European child health advocates, professionals, policy makers, and citizens, have a duty to act urgently and effectively. Every child has the right to life and the best possible health.

Figure 22. A whole systems plan for European child health

A final and unifying recommendation presented in paper IV should help focus attention on urgent problems, ensure accountability, and serve towards strengthening health systems. A Countdown Child and Adolescent Survival initiative is proposed, based on the Countdown initiative for low and middle income countries which helped many countries reach their Millennium Development Goals to reduce child mortality. The UK, and indeed other European countries, could learn from the same mechanism to focus attention on important areas of child health.

An independent Countdown collaboration could be established across disciplines and institutions, providing a bridge between the technical and the political,
identifying gaps in knowledge and practice, reporting annually on progress, and proposing new actions to promote child survival. Setting goals, targets, and indicators will direct and maintain efforts towards reducing child mortality, and help ensure a process of accountability for action. The Collaboration’s attention should encompass a continuum of care from pre-pregnancy through maternity, birth, postnatal, infancy, childhood, and adolescence; and stretch across boundaries in place from home and community to health care facilities and non-health sectors. Such a broad approach to the UK Countdown will help ensure optimal efforts towards the twin goals of mortality reduction and maximal gain in health and wellbeing. Learning from the Countdown to 2015 collaboration for low and middle income countries towards achieving the Millennium Development Goals, and linking efforts to the global work for Sustainable Development Goals for 2030, will help secure the best possible chances for success (128).

The UK could, in theory, achieve the same mortality rate as other European countries where children have a greater chance of surviving. Although there is no single cause for the disparities between the UK and other countries and no simple solutions, it is possible to make reasoned policy and practice recommendations. The messages are stark and crucial, and they apply to the UK and throughout Europe. Poverty and inequity are harmful to children. Social protection is life-saving medicine for the population. Health systems and services, and public health interventions that save children’s lives must be financed, implemented and incentivised appropriately, and sustained. It is a grave injustice that children do not enjoy the highest standards of health and wellbeing and the greatest chances to fulfill their individual potential in life. That children in the UK are dying unnecessarily shames the nation.

Science and advocacy are the way to achieve strong European child health systems and promote child health, child survival, and child rights. Real and sustained improvements in European child health can happen if political will across the EU can be brought to bear on the problems facing children today.
7. CONCLUSIONS

7.1. High level conclusions

- Child survival and health in Europe are improving, but more in some countries than in others.
- Child health systems are not adapting sufficiently to meet needs.
- Important determinants of child health that lie outside health systems are amenable to policy, and action in these domains is essential for improving child health.
- A whole-systems approach is needed to strengthen European child health systems and services and thereby improve child health.

7.2. Detailed conclusions

- Child health systems in Europe are not optimally meeting children’s current health needs nor adapting sufficiently to children’s evolving health needs. Avoidable deaths, suboptimal health, and inefficient use of health services are the result.

- If all countries in Europe improved their child mortality rates to match the country with the best rate (Sweden), over 6,000 deaths per year could be prevented among children in the European Union.

- Goals can be helpful. Comparisons between countries stimulate research and policy action to address important problems.

- Politicians and policy-makers have choices; most of the important problems of European child health are amenable to policy and practice changes that are realisable.

- Maximal health gain is most likely to result from European countries focusing their attentions on the problems of the majority of their young populations, i.e. everyday healthcare and the health concerns of ordinary children with common problems.

- Chronic care models for children are needed to improve care, ensure better quality of life for children and families, and improve non-communicable disease outcomes. Several countries have made progress in developing chronic care services, offering lessons for others.

- First contact care services and outcomes for children in Europe are highly variable. Flexible models with teams of primary care professionals trained in child health and working closely together may offer a way to balance expertise with access.
• Child health indicator sets with reliable and uniform systems for collecting data would facilitate efforts to improve services. Child health research is still a small field but there is growing awareness of the importance of investment in the earliest years. Individual countries and EU-wide organisations should review investment in child health and health services research.

• Politicians and policy makers should do more to translate high-level goals for child health into implemented policies with accountability structures to ensure their delivery. Investment in social protection policies for the earliest years and the most vulnerable children will improve health, reduce inequities, and accumulate advantages throughout the life-course.
8. FUTURE RESEARCH

• Comprehensive assessments of European child health systems are needed, and should be conducted regularly to track progress and promote accountability.

• A systematic review of the evidence on how best to organise everyday healthcare for children and young people is needed. This is underway now and should provide useful and important information since health systems throughout Europe are struggling with re-organising services to adapt to the rise in chronic conditions.

• Amenable mortality for children and young people has yet to be defined. An agreed definition and reliable indicators would enable routine measurement and monitoring of amenable mortality, helping to direct policy actions accordingly.
  o A Countdown Collaboration for the UK has been proposed, and a data and research working group would likely focus on defining amenable mortality and agreeing indicators.

• Establishing a set of internationally agreed validated standardised indicators of quality of care for children’s health services is an urgent requirement.
  o An international benchmarking process is likely to be part of an EU-wide research programme that has recently been granted funding. The MOCHA programme (Models of Child Health Appraised) will describe and evaluate children’s primary health care models in all 30 EU/EEA countries, as well as develop measures of quality, outcome, cost, and workforce, assess effects on equality and continuity of care, and obtain stakeholder views. The results will inform the choice of optimal model(s) of children’s primary care with a prevention and wellness focus, and identify factors which might facilitate their adoption.

• Finally, it is necessary to put some specific recommendations from this dissertation into practice and evaluate them. To deliver high quality responsive care for children and young people, we need an integrated everyday healthcare model that strengthens primary care, brings physical and mental health together, and ensures that health promotion is at the core of clinical practice.
  o A child health services transformation programme using public health principles is underway in south London, with a rigorous academic evaluation integral to the programme.
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Child Health, Health Services and Systems in UK and other European countries

How do European countries compare in child health and child survival?

How do different child health services, systems, and wider determinants exert long-term influences for good or harm?

Why do some countries seem to do better than others in securing and promoting their children’s and young people’s health and wellbeing?

And what can we do to make things better?

This thesis explores some of these difficult but important issues, describes serious problems in child health, and offers recommendations for European countries to ensure a healthier future for children.