IMPROVING HEALTH SERVICES FOR ADOLESCENTS IN ENGLAND

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I, Dougal Hargreaves, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed ……………………………………………………….

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Professor Russell Viner

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The Department of Health had no influence on the study design, analysis or presentation of the original research presented in this thesis. All views expressed are my own.

ABSTRACT

Research objectives

1. Characterise adolescent (10-19 years) use of NHS hospital services in England, including inequality effects.
2. Analyse the inclusion, experience and priorities of adolescent patients in national surveys and compare these with other age groups.
3. Assess the validity of English national quality standards for adolescent health services in inpatient and emergency department settings.

Methods

Secondary analysis of national data including

- Hospital Episode Statistics on inpatient activity among adolescents in England (1999/2000-2010/11).
- Health Survey for England data on general measures of health and health risk among those aged 0-24 between 1999 and 2009.
- Data from 38 national surveys undertaken between 2001 and 2011 (working in collaboration with the Picker Institute Europe).

Findings

- Healthcare activity increases throughout adolescence, particularly in females.
- Adolescent inpatient activity has increased faster than that of younger children (aged 2-9) over the past decade, and adolescents have higher average activity rates.
- Between 1999 and 2009, health inequality among young people increased for smoking but decreased for healthcare activity.
- Children under 16 account for less than 0.6% of participants in recent national patient surveys.
- Young people aged 16-24 report the poorest patient experience of any age group.
- Compared to older adults, young men's satisfaction with inpatient care was more strongly correlated with pain control, and young women's satisfaction was more strongly correlated with perceived respect and dignity and provider

- Data covering the majority of *You're Welcome* criteria show that they function well as a measure of quality for adolescent inpatient and Emergency Department services.

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PUBLICATIONS

Some of the original material presented in this thesis has been published in scientific journals. Details are presented below.

Articles in peer-reviewed journals

Hargreaves DS, Sizmur S, Viner RM. Do Young and Older Adults Have Different Health Care Priorities? Evidence From a National Survey of English Inpatients. *J Adolesc Health. 2012.*
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Hargreaves DS, McDonagh JE, Viner RM. Validation of *You're Welcome* quality criteria for adolescent health services using data from national inpatient surveys in England. *J Adolesc Health* 2012
[Epub: http://dx.doi.org/10.1016/j.jadohealth.2012.04.005]

Hargreaves DS, Viner RM. Children's and young people's experience of the National Health Service in England: a review of national surveys 2001-2011.
Arch Dis Child 2012;**97**:661-666

Abstracts in peer-reviewed journals

Hargreaves DS, Djafari Marbini A, Viner RM**.** Use of concentration indices of Hospital Episode Statistics data to monitor inequality among English children and young people (1999/2000-2009/10). Lancet 23 Nov 2012.

Hargreaves DS, Djafari Marbini A. Did health inequality increase in English children and young people between 1999 and 2009? Evidence from two cross-sectional surveys and inpatient activity data. (oral presentation at Social Science & Medicine conference, London, 12th September 2012)

Hargreaves DS, Djafari Marbini A. Use of healthcare services by young people in England: an analysis of national activity data by age, sex and International Classification of Disease chapter. *Arch Dis Child* 2012;**97**:Suppl 1 A76-A77 doi:10.1136/archdischild-2012-301885.186

Djafari Marbini A, Hargreaves DS. Children and young people's use of emergency and inpatient services by age and socio-economic status: an analysis of national hospital episode statistics in England. *Arch Dis Child* 2012;**97**:Suppl 1 A146-A147 doi:10.1136/archdischild-2012-301885.349

Hargreaves DS, Viner RM, McDonagh JE. What do young people value in health services? Validation of the *You're Welcome* quality criteria against data from 2 national inpatient surveys in England. *Arch Dis Child* 2012;**97**:Suppl 1 A77 doi:10.1136/archdischild-2012-301885.187

RESEARCH CONTRIBUTIONS AND THE ROLE OF THE CANDIDATE

The original research in this thesis is divided into three sections, corresponding to the three methods chapters (2-4) and three results chapters (5-7). I conceived the idea for each of the analyses myself, performed all analyses except one, and wrote the first draft of all published material. However, many people contributed to different aspects of the research. The purpose of this section is to describe these contributions and the role I played in all the material presented. Co-authors of publications and submitted articles arising from each section are listed, as well as those whose help is acknowledged. My principal supervisor, Prof Russell Viner was involved in all the work described and was a co-author on all publications except one.

Health service activity (Chapters 2 & 5)

Role of the candidate

I accessed Hospital Episode Statistics (HES) data for 2008/9 directly while working at the Department of Health. Inpatient HES data from 1999/2000 to 2010/11 were supplied by Northgate Information Solutions, supported by a research grant from the Department of Health to the Policy Research Unit at the UCL Institute of Child Health. Health Survey for England data and health service data from Australia and New Zealand are publicly accessible. I performed all analyses of these data.

Co-author

Ms Aghileh Djafari Marbini (Imperial College Healthcare Trust) helped to revise the submitted manuscript on health inequalities and checked the methodology and calculations.

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Young people’s experiences and priorities in healthcare (Chapters 3 & 6)

Role of the candidate

This section draws on survey data collected by the Picker Institute Europe and was done in collaboration with Dr Steve Sizmur, senior statistician at the Picker Institute. For the analysis presented in sections 3.1, 3.2, 6.1, 6.2, Dr Sizmur provided modified datasets with seven age bands, rather than the publicly accessible datasets with 5 age bands. I then analysed the data myself.

For the comparison of young and older adults' priorities (sections 3.3, 6.3) Dr Sizmur calculated the domain scores and the correlation coefficients between domain scores and overall satisfaction. I then performed all the relevant statistical tests.

Co-author
Dr Steve Sizmur (Picker Institute Europe)

Revision and validation of *You're Welcome* standards (Chapters 4 & 7)

For the validation studies *(sections 4.1, 4.2, 7.1, 7.2)* I performed all analyses myself, using the modified datasets described above.

Co-author: Dr Janet McDonagh (Birmingham University) helped to revise the manuscript.

ETHICS APPROVAL

All the original research relating to health service activity (Chapters 2 & 5), patient experience (Chapters 3 & 6), and validation of the You're Welcome standards (Chapters 4 & 7) used secondary analysis of anonymised, national data. Therefore, no ethical approval was necessary.

LIST OF ABBREVIATIONS

AYPH	Association for Young People’s Health
BMA	British Medical Association
ChiMat	Child and Maternal Health Observatory
CI	Confidence interval
CYPOF	Children and Young People’s Health Outcomes Forum
DH	Department of Health
DRG	Diagnosis Related Group
ED	Emergency Department
FCE	Finished Consultant Episode
fMRI	Functional Magnetic Resonance Imaging
GP	General Practitioner
HES	Hospital Episode Statistics
HSE	Health Survey for England
ICD10	International Classification of Disease 10
IMD	Index of Multiple Deprivation
IS	Inpatient Survey
LGBT	Lesbian, Gay, Bisexual and Transgender
LSOA	Lower layer Super Output Area
MDG	Millennium Development Goal
MSOA	Middle layer Super Output Area
NCB	National Children’s Bureau
ONS	Office for National Statistics
RCGP	Royal College of General Practitioners
RCN	Royal College of Nurses
RCPCH	Royal College of Paediatrics and Child Health
THDS	Teenage Health Demonstration Sites
UKDA	United Kingdom Data Archive
UNCRC	United Nations Convention on the Rights of the Child
WHO	World Health Organisation
YPDP	Young People’s Development Programme
YPHSIG	Young People’s Health Special Interest Group
YPS	Young Patients’ Survey

YW	*You’re Welcome*

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INTRODUCTION

Overview of thesis structure

Entitled 'Improving health services for adolescents in England' this thesis investigates key aspects of adolescent services within the English NHS and aims to contribute to a robust evidence base for improving the quality of service provided to young people.

A wide range of frameworks and assessment tools have been published for the purpose of assessing health services, including comprehensive tools such as the Framework for Health System Performance Assessment, published by the WHO,(1) and more targeted strategies for improving healthcare quality, such as that published by the Health Foundation.(2) Key components of both approaches are to start by analysing how services are used, before moving on to evaluate service quality against an agreed set of standards. Quality improvement frameworks (such as the Health Foundation framework above) then emphasise the importance of using robust, validated tools to evaluate the impact of any intervention.

The original research within this thesis is structured following the three steps identified above. Firstly, I use routinely collected national data to investigate adolescent use of hospital services, and how activity varies with age, sex and socioeconomic status. Secondly, I use indicators derived from the WHO principles of adolescent friendly care (3) to assess the quality of service provided. As part of this analysis, I investigate whether adolescents have different healthcare priorities to older adults (i.e. whether service quality should be defined differently for this age group). Lastly, I assess the validity of the 'You're Welcome' quality standards (4) (the Department of Health's chosen tool to assess and monitor improvement in adolescent services).

This structure also maps well to the 5 principles of adolescent friendly services identified by the WHO (3) which are presented in section 1.1. The first step relates to equity and accessibility, for which the methods are presented in Chapter 2 and the results in Chapter 5; Chapters 3 presents the methods used to assess the acceptability and appropriateness of current services, and Chapter 6 the results of these analyses. Although clinical effectiveness is not addressed directly, the research in Chapters 4 & 7 demonstrates the validity of You're Welcome as a measure of service quality, facilitating development of effective interventions to improve patient experience and engagement in the future.

Chapter 1. Policy and research background relating to adolescent health services in England

Introduction
1.1 Overview of international policy and research literature
1.2 English policy context 2002-2012
1.3 Patterns of healthcare activity and impact of socio-economic status
1.4 Young people's experience of NHS services
1.5 Participation and health engagement
1.6 Physical, psychological and social transitions during adolescence
1.7 Epidemiology of adolescent health
1.8 Neuroscience perspectives on the adolescent brain
1.9 Wider determinants of adolescent health.
1.10 Research priorities and gaps in existing literature

Introduction

The purpose of Chapter 1 is to review research and policy areas relevant to adolescent health services in England. The Department of Health funded this work with the intention that it would focus on specific policy priorities related to adolescent health services. I have therefore taken a pragmatic approach that aims to balance detailed analysis of key areas with more selective discussion of relevant material from a number of wider fields. Throughout the introduction, the rigour and relevance of previous research to adolescent health services in England are discussed. The processes of searching, assembling and appraising the literature differ slightly between sections and are described in detail at the beginning of each section. Where possible, one or more systematic reviews of each area are discussed, with an appraisal of the search strategy used and the validity of the conclusions drawn.

The first two sections provide an overview of recent milestones in policy and research, from both international (1.1) and English perspectives (1.2). Sections 1.3 to 1.5 are broadly aligned with the main content of the thesis, reviewing what is already known about how young people use NHS services (1.3), their experience of NHS care (1.4), and the importance of participation and health engagement (1.5). Section 1.6 provides an overview of transitions in adolescence, before sections 1.7 to 1.9 review some key findings from other relevant disciplines, including epidemiology (1.7), neuroscience (1.8) and social psychology/public health (1.9). Section 1.10 reviews the policy and research priorities emerging from the chapter and leads into the research objectives, presented in section 1.11.

The potential range of relevant background material is large, covering the health related behaviour and preventive, primary and specialist care needs of over 6 million adolescents in England. For example, the literature within the fields of adolescent epidemiology, health inequality or neuroscience alone would exceed the scope of a single thesis. It is recognised that the breadth of material covered limits the depth of analysis that is possible in each area. However, within these constraints of space, an effort is made to provide a rigorous analysis that minimises the risk of bias and focuses on studies with the most relevant to English services.

Sections 1.3 to 1.5 aim to provide a more comprehensive review of their topics. However, considerations of space again mean that detailed discussion is largely restricted to literature on English adolescents; studies on non-English populations are only included to provide wider context or where no equivalent English studies have been published. These studies include some material from high, middle and low income countries, consistent with evidence that adolescent healthcare shares many challenges globally, and health services in very different contexts have much to learn from each other.(5)

1.1 Overview of international policy and research literature

The health and well being of young people have never had a higher profile, both in the UK and internationally. UNICEF have moved from a traditional focus on young children to advocate more strongly for the needs of adolescents,(6) a shift also seen among other UN bodies such as the UN Development Programme. The International Year of Youth, August 2010-2011,(7) highlighted the benefits to society of investing in and engaging with young people.(8) Where this has not happened, young people have shown their determination to influence society and have been at the heart of movements fighting for democracy in parts of the Middle East and a fairer distribution of resources worldwide.(9) Meanwhile, Western economists talk of a ‘lost generation’ as unemployment and ill-health related to economic circumstances hit the young particularly hard, with potential life-long consequences.(10;11) At least in Britain, this is matched by rising fear, lack of empathy and negative views of young people among older adults.(12)

The decade from 2002 to 2012 saw increasing interest in adolescent health - from both research and policy perspectives, and at both national and international levels. This section reviews important milestones during the past decade and sets the context for a review of specific policy developments in England (presented in section 1.2) which have particular relevance for the research presented in this thesis. Key policy documents were identified through a search of websites belonging to the World Health Organisation and English Department of Health. Research articles in this section are largely restricted to those cited within relevant policy documents and/or research published within the context of policy advocacy. For example, the Lancet adolescent health series in 2007 explicitly aimed to 'highlight an area of health care that remains neglected, marginalised or ignored in many countries'.(13) A more systematic review of the research literature is presented in subsequent sections.

Adolescent health and the Millennium Development Goals

Many global health and development policies over the last decade have been focussed on achieving the Millennium Development Goals (MDGs),(14) which are listed below.

1. Eradicate extreme poverty and hunger
2. Achieve universal primary education
3. Promote gender equality and empower women
4. Reduce child mortality
5. Improve maternal health
6. Combat HIV/AIDS, malaria and other diseases
7. Ensure environmental sustainability
8. Develop a global partnership for development.

Although there are no age-specific targets for adolescents (unlike infants and children under 5), the World Health Organisation (WHO) has emphasised the importance of adolescent girls in particular, stating 'Achieving MDGs 1-6 (including reducing adolescent girls.’(15) The focus on adolescent pregnancy is endorsed by UN Secretary General Ban Ki Moon in the 2011 Global Strategy for Women and Children’s Health.(16) However, the WHO recognised early that many aspects of adolescent health were not directly covered by the MDGs and warranted separate policy and research attention. These included mental health conditions (cause of the greatest global burden of disease in young people),(17) violence and injuries (which disproportionately affects young people and are the greatest cause of death in this age group), (18) sexual coercion and violence, and substance misuse.

World Health Organisation adolescent-friendly health initiatives

One such policy initiative, running in parallel to the MDGs over the past decade, has been advocacy for, and development of, adolescent friendly healthcare. Much interest was triggered by the WHO Agenda for Change report in 2002,(3) which argued that

> *‘Health services often regard adolescents as a healthy group who do not need priority action, and so provide a minimum subset of adult or paediatric services with no adjustment for their special needs. There is evidence that many young people regard such health services as irrelevant to their needs and distrust them. They avoid such services altogether, or seek help from them only when they are desperate.*’

In response, the authors proposed a range of factors that make services more accessible, acceptable, appropriate, equitable and effective for young people. One key element was competent, motivated staff, skilled at communicating with adolescents and able to offer a confidential, non-judgemental service. They particularly emphasised the importance of equity, involving non-discriminatory services that reach out to marginalised or vulnerable groups. Several examples of best practice were described, from information services in Indian schools and colleges, a human rights-based initiative in Costa Rica, a peer educator project promoting sexual health in Tanzania, to health centres for street children in the Philippines. The diversity of these case studies highlighted many common themes, but also the need to develop services in partnership with service users, so as to be appropriate to the local context.

Over the following ten years, the WHO has progressively developed its vision for adolescent health services in different global contexts, with different regions

At a WHO-Europe meeting in Edinburgh in September 2009,(19) representatives of 35 member states came together to share experiences of developing more youth-friendly services. Case studies from different countries took different perspectives on the challenges they faced: for example, the legal and policy context in Sweden, illustrated by practical use of the UN Convention on the Rights of the Child; the impact of health system reform on school health provision in the Republic of Moldova; and social determinants of adolescent health in the Russian Federation.

Although the medical needs and social transition of adolescence often differ between high and low income countries,(20) other WHO regions have demonstrated the importance of these principles in a wide variety of global contexts. For example, adolescent friendly services have been identified by the Pan American Health Organisation as important in tackling social inequalities in health(21) and by WHO Africa in responding to HIV/AIDS.(22) Going beyond the focus on anti-retroviral drugs, pursued by some international organisations, WHO Africa has highlighted the importance of a youth-friendly approach, particularly in cultural contexts where stigma and religious conservatism made many young people reluctant to access health services or be tested for possible infection. The principles of confidential, non-judgemental services, which are easily accessible without financial or cultural barriers, have been extensively promoted.

In 2009, the WHO published a quality assessment guidebook for adolescent health services.(23) This built on national tools that had previously been used in the UK, Zimbabwe and South Africa and was extensively piloted worldwide, including projects in the Russian Federation, Mongolia, India, Kenya and Indonesia. Using the 5 dimensions described above (equity, accessibility, acceptability, appropriateness, effectiveness) they list detailed characteristics of adolescent friendly services and give project-management guidance for how services can be improved. With a broad degree of consensus established on these principles, the next challenge was to see how they could be adapted and applied to specific national contexts. In many cases, part of this process involved integrating adolescent-friendly standards with the UNICEF agenda to secure children’s rights and promote participation.

National policy reports

The challenge set out by the WHO and others has resulted in a variety of policy responses by governments worldwide. At the 4-yearly conference of the International Association of Adolescent Health, held in Kuala Lumpur in 2009, I presented English policies relating to adolescent friendly services, alongside similar presentations on policies in India, Thailand, and Malaysia. This session showed the range of contexts in which young people friendly services were being developed, with common themes of accessibility and confidentiality being addressed in very diverse ways in different countries. However, the majority of projects presented had been established in response to a specific local need or a distinct, marginalised group of young people. Examples included access to sexual health services in India/Thailand or the needs of care leavers or young HIV positive people in England (discussed in more detail in section 1.2).

Perhaps the first comprehensive national review of adolescent health and health services was performed by the US Academy of Medical Science in 2009, where they suggested that ‘the current system of health services in the United States is ill suited to providing the appropriate mix of clinical and preventive services to adolescents.’ Entitled Adolescent Health Services: Missing Opportunities,(24) it addresses a range of key issues, including screening and health promotion, improved training and accreditation of health professionals, and the needs of vulnerable young people, especially those with mental or behavioural disorders,

In England, no such unified review has been performed but many similar themes have been addressed in national reports, including transition from paediatric to adult services,(25) health promotion between the ages of 5-19,(26) the Kennedy report into NHS services for children and young people, (27) and the *You’re Welcome* standards for young people friendly care. (4) All these are discussed in more detail in section 1.2.

Research context

In parallel to policy development over the past decade, there has been growing research interest in adolescent health. Much of the early work around the time of the 2002 WHO or geographical context. For example, in England a 2005 paper by Viner and Barker raised awareness of the needs of young people (28) while two further papers by Viner documented the limited provision of adolescent services (29) and the higher quality experience of young patients treated in adolescent wards. (30)

The Lancet Adolescent Health series 2007(13) attempted to bring many complementary strands of research together to present a compelling overview and call for action. The editorial noted that the generation of adolescents was then the largest in history, with almost half of the world's population being younger than 25 years.(13) It goes on to note that, although these young people 'faced far more complex challenges to their health and development than their parents did', health services for them were 'neglected, marginalised, or ignored in many countries.' Alongside articles covering specific aspects of adolescent health (sexual and reproductive health, mental health, substance use, chronic conditions), a review by Tylee et al(31) identified three main approaches which had been used to improve the performance of primary healthcare services for adolescents:

- provision of guidelines
- provider training
- quality-improvement strategies incorporating provide training.

Since 2007, research has continued in many of these areas, notably the epidemiological transition towards greater morbidity and mortality in adolescence than any other period of childhood outside infancy (discussed in more detail in Chapter 1.6). A second Lancet series on adolescent health, published in May 2012, identified several areas of progress over the previous 5 years, as well as many ongoing challenges. The core four articles focussed on adolescence as a foundation for future health,(9) adolescence and the social determinants of health, (32) an international comparison of adolescent outcomes and data availability, (33) and a review of adolescent health interventions from both health and economic perspectives.(34)

Compared to adolescent epidemiology, health services research has perhaps made less progress in recent years. Unlike the previous Lancet series, the 2012 series included only one reference to adolescent friendly primary care services and no mention of secondary care or other contexts. A tool based on the WHO standards has now been validated for primary care service,(35) but there have been few efforts to extend the standards to secondary care settings, despite increasing recognition of the importance of hospital services for population health.

Economic aspects of adolescent health policy

The current financial climate has reinforced the importance of making an economic case for investing in health services. The cover of the 2012 Lancet series on adolescent health read:

> '*Failure to invest in the health of the largest generation of adolescents in the world's history jeopardises earlier investments in maternal and child health, erodes future quality and length of life, and escalates suffering, inequality, and social instability.'*

Health economic aspects of health services for adolescents continue to be underdeveloped. As part of the 2012 Lancet series, Catalano et al analysed the costs and benefits to tax payers of investment in health promotion and wider community interventions into adolescent engagement.(34) OECD data show that governments in all developed countries spend large sums on services for children and young people, with spending in the USA and some other countries skewed towards adolescence, while spending in Nordic countries focuses more on the early years.(36) However, the bulk of this spending, particularly in adolescence, relates to education provision so cannot be used to compare health-related spending.

While the importance of early influences are not in doubt, Michael Marmot,(37) UNICEF,(6) and others have emphasised the importance of a life-course approach to health and life opportunities, with investment in early years followed by ongoing investment throughout childhood and adolescence. A comprehensive US review (38) found that investment in early years was the most cost-effective but that 'remediation in the adolescent years can repair the damage of adverse early environment.' Similarly, the contribution of economic inequality to health is well-established (37;39), but an understanding of adolescence as a key period in the emergence of health inequalities (32;40) is more recent, and the picture may be complicated by the existence of other social hierarchies in this age group.(41)

benefits of adolescent health services. Economic modelling of adolescent health interventions has been identified as a priority for future research by a member of the Lancet's editorial team (personal communication: Sabine Kleinert, at a seminar on adolescent health at the London School of Hygiene and Tropical Medicine, May 2012).

1.2 English policy context 2002-2012

Having introduced the international research and policy context in section 1.1, this section reviews the development of specific policies related to health services for young people in England over the last decade. As above, the following publications were identified by searching the websites of the English Department of Health, Department for Education and Skills/Department for Children, Schools and Families, Royal College of Paediatrics and Child Health, supplemented by a widely cited report from the British Medical Association.

Mirroring the international agenda, UK concern about health services for adolescents has been increasing in recent years. Table 1 presents the principal policy publications related to adolescent health in England over the past decade. In addition to these publications, another important development over the past decade has been the establishment of two new organisations to promote adolescent health: the Association of Young People's Health (AYPH) and the Young People's Health Special Interest Group (YPHSIG). The AYPH was formed in 2008 and aims to create 'a focus for everyone working in the field of young people's health across the UK'.(42) The YPHSIG is an interest group within the Royal College of Paediatrics and Child Health, although it welcomes members from other medical and non-medical professions.(43)

Much early impetus for adolescent health policy in England came from professional organisations. 'Bridging the Gaps, Healthcare for Adolescents'(44) was published in 2003 and represented a coordinated effort by several royal colleges to raise the profile of adolescent health. A particular focus was the difficulties faced by many young people during the transition from paediatric to adult services. These findings were reinforced by the BMA Board of Science and Education report into adolescent health, also published in 2003.(45)

Table 1: Selected policy publications relevant to adolescent health, England, 2002-2012.

Date	Title	Organisation
2003	Bridging the Gaps: Health Care for Adolescents(44)	RCPCH, RCGP, RCN, and other members of the Intercollegiate Working Party
2003	Adolescent Health(45)	BMA Board of Science and Education
2004	National Service Framework for Children, Young People and Maternity services(46)	DH
2005, 2007, 2009, 2011	*You're Welcome* standards for young person friendly care (47-50) (various versions)	DH
2006	Transition: Getting it right for Young People(51)	DH
2007	Aiming High for Disabled Children (AHDC): Better support for families (52)	Department for Education and Skills
2007	A Transition guide for all services: key information for professionals about the transition process for disabled children(53)	DCSF/DH
2008	Progress report on health inequalities(54)	DH
2008	Under their skins: tackling the health of the teenage nation(55)	DH (Chief Medical Officer's report)
2008	Transition: Moving on Well(25)	DH
2008,2009	Evaluation of the Teenage Health Demonstration Sites(56;57)	Institute of Education
2009	Healthy Lives, Brighter Futures(58)	DH
2009	Healthy Child Programme 5-19(26)	DH/DCSF
2010	Kennedy Report into NHS services for children and young people(27)	DH
2011	Not just a phase: a guide to participation(59)	RCPCH
2012	Health and Social Care Act(60)	DH
2012	NHS Atlas of Variation in Healthcare for Children and Young People(61)	NHS Rightcare

2012	Report of the Children and Young People's Health Outcomes Forum(62)	DH

Notes to Table 1.
DH Department of Health, DCSF Department of Children, Schools and Families, RCPCH Royal College of Paediatrics and Child Health, RCGP Royal College of General Practitioners, RCN Royal College of Nursing, BMA British Medical Association.

Health inequalities

Additional policy momentum for adolescent health was provided by the government programme to reduce health inequalities. On taking office in 1997, this was a key priority for the New Labour government, which embarked on an inequality strategy later described as more 'systematically developed, better resourced, more stringently implemented and more extensively monitored' than anywhere else in Europe.(63;64) Although infant mortality and life expectancy were the principal targets, the strategy also monitored a number of additional indicators relating to young people, such as rates of teenage pregnancy. Progress was uneven – both geographically and over time - but the trend between 1998 and 2006 showed a reduction in under-18 conception of 12.9% and a fall in births of 23%.(65) Inequality in teenage pregnancy rates decreased in absolute terms but not relative terms over this period.(66)

The inequalities strategy provided important support to the development of adolescent friendly services. A 2009 report stated the Government's view that:

'Services need to make sense to the target group if they are to be used and be effective. This is an important consideration in delivering services that relate to and meet young people's needs and approach to life.'(66)

An adolescent friendly approach was seen as the best way to support the most vulnerable young people to engage with their own health and make the best use of health services. Based on a philosophy of participation and co-production with young people, the first *You're Welcome* (*YW*) standards were published in 2005 with the aim that professionals and service managers would work with young users of their service to improve standards. Further development of *YW* is described in detail below.

Chief Medical Officer annual report

A major boost to the policy profile of adolescent health in England came with the publication of the 2007 Annual Report by the Chief Medical Officer.(55) Entitled, 'Tackling the health of the teenage nation', this emphasised that

> *'The effects of poor health during the teenage years can last a lifetime. Keeping adolescents healthy is a valuable investment in the nation's future.'*

The report highlighted a number of issues discussed above and presented their relevance to an English context, ending with a series of recommendations which laid the foundations for much subsequent policy development, including the Healthy Child Programme from 5 to 19 years old,(26) and revision of the *You're Welcome* criteria. For the Department of Health, this report also marked the first high-profile recognition of the distinct needs of young people, stating 'It is clear that young people have special needs… Health care services need to be designed, again with the help of young people, which address those needs.'(55)

Teenage health demonstration sites

Linking with the inequality strategy described above, a range of pilot projects were conducted from 2005 onwards to investigate how services could work more effectively with young people. These included the Teenage Health Demonstration Sites (THDS),(56) the Young People's Development Programme (YPDP)(67) and *You're Welcome* standards for young people friendly care.(50)

The first of the demonstration sites was a project for HIV positive young people in Hackney, which addressed the barriers perceived by many patients in accessing mainstream services. A parallel project in Northumberland explored the needs of vulnerable young people in a remote rural setting, as well as more specific needs such as more joined up approach, offering a range of accessible services to young people affected by issues such as homelessness and commercial sex work. A common theme at the majority of THDS project was the role of dedicated youth workers who had the skills and time to build trust with young people.

Alongside qualitative evaluations of this work,(56;57) the Department of Health also funded a prospective comparison study of the Young Person Development Programme in 54 youth service sites across England.(67) This programme was based on the US Children's Aid Society's Carrera model, which demonstrated significant social and financial benefits over a period of many years. In New York, for example, female participants in the programme reported delayed sexual experience, increased use of contraception and a lower rate of pregnancies.(68) Other evaluations of this programme have shown that social benefits can translate into lower costs to the state, from both health and wider social consequences.(69) The programme delivered in the English study adapted some elements of the US version, providing a more targeted intervention to the most vulnerable young people. The evaluation, published in the BMJ in 2009,(67) found that both staff and young people were positive about their experience of the programme. However, rates of teenage pregnancy, early heterosexual experience and expectation of teenage parenthood were significantly higher in the intervention group compared to controls.

The authors comment that this finding could be attributed to increased contact with high-risk peers, although the sites were not randomised so they cannot exclude the possibility of confounding factors. Although the YPDP evaluation only followed up participants for 18 months, similar findings have been seen in previous studies, reviewed by the social psychologist Timothy D. Wilson in his book Redirect. (70) This literature is discussed in more detail in section 1.9.

You're Welcome quality standards for adolescent healthcare services

Of the early initiatives discussed, the longest standing has been the *You're Welcome* standards for young people friendly care. These were developed in partnership with young people at the 4 demonstration sites introduced above, and were first published in 2005 before being updated in 2007 and a self assessment tool published in 2009.

They describe key features of a young person friendly service, with 8 core criteria (Access, Publicity, Confidentiality/Consent, Environment, Staff, Joined up working, Participation of young people, and Health issues for young people) and two additional criteria to be used where relevant (Child and Adolescent Mental Health Services and Sexual Health). Detailed sub criteria assess the service on a range of question, combining practical and professional issues – e.g. accessibility by public transport, wheelchair access, whether the young person can ask to see a male or female clinician, whether young people can be seen without their parents/carers. Services used self-assessment to identify and address weaknesses in their services, with the *You're Welcome* mark being awarded when a sufficiently high standard was reached. The accreditation process ensured consistency and quality assurance, with young people and *You're Welcome* co-ordinators reviewing the self-assessment report and inspecting a proportion of services.

Targeted specifically at primary care and community services, this process led to an active network of regional and local co-ordinators, with the *YW* standards being used by around a quarter of all child health services by 2011.(50) To this point, there were no published *You're Welcome* standards targeted at inpatient or specialist services.

Health promotion

Another important policy development was the review of health promotion services by Professors David and Sue Hall in 2009, leading to publication of the Healthy Child Programme 5-19.(26) Following the model of the successful HCP 0-5,(71) this policy aimed to 'make everywhere as good as the best,' and combined a synthesis of research literature with practical implementation guidance for professionals, managers and commissioners. Taking a holistic approach to young people's needs, this programme aimed to ensure better integration, communication and co-ordination between all relevant stakeholders. These included: health, education, and social services professionals; children, young people and their families; third sector and wider community groups. The programme also suggested a number of ways in which health services could promote young people's engagement with their health, from an invitation 'birthday card' sent by GPs to all those turning 16, to better identification and support for emotional health and well-being concerns throughout adolescence.

Recent policy development 2009-2012

Sir Ian Kennedy was commissioned by the Department of Health to investigate cultural barriers to improving NHS services for children and young people. Published in 2010, his report found that service quality was uneven, with examples of excellence frequently 'pockets in a sea of mediocrity'.(27) These findings are supported by a recent study showing that the NHS performs poorly on many indicators for children and young people when compared to other European countries, (72) and that transition to adult services is often done poorly.(73) Two areas highlighted in the Kennedy report were:

- the NHS' lack of responsiveness to the views of young people and their families
- the poor experience of many young people during the transition from paediatric to adult services.

The report proposed that satisfaction should become the single criterion for assessing service quality, in a way that would incorporate the satisfaction of young people and their families with professionals' satisfaction regarding clinical effectiveness.

In common with all areas of health, adolescent health policy since the general election in May 2010 has been dominated by the Health and Social Care Act 2012 (60) and the associated Public Health White Paper.(74) These will not be described in detail but various important elements will be discussed in the following sections. Many policy areas have shown continuity with previous work, including publication of the revised *You're Welcome* standards in 2011, and development of the themes of health inequalities and patient involvement. However, the extensive restructuring has reduced the resources and attention available to improve child and adolescent health in many areas of national policy development and local service management. The localism approach has also moved resources away from central initiatives, so that, for example, *You're Welcome* no longer has a national accreditation system.

Recognising some of these difficulties, in January 2012 the Secretary of State commissioned a forum of experts to advise on the best ways of monitoring and holding decision makers accountable for the health of children and young people under the NHS reforms.(75) The forum included a cross-cutting group advising on adolescent health issues. The full report was published in July 2012(62) and makes a number of recommendations related to adolescent health, including

- the need to include children and young people in all relevant national surveys
- a new outcome indicator and renewed focus on improving transition from children's to adult services
- a focus on delivering age-appropriate care, with particular reference to teenagers.

1.3 Patterns of healthcare activity and impact of socio-economic status

This section investigates evidence about how young people use NHS services in practice, including the degree to which this is influenced by socio-economic factors.

In contrast to the extensive literature about mortality and morbidity trends in adolescence (discussed in 1.7), relatively little collated data is available about patterns or trends in healthcare activity among young people. The 2012 Lancet paper by Patton et al investigated adolescent health data from a wide range of international sources and found that health service use was one of only two indicators for which no national data were readily available for the UK or any other country.(33)

The following review is based on a non-systematic Medline search of literature relating to English healthcare activity for children and young people in each setting. This search was performed in April 2012 and used search terms including 'children/young people', 'healthcare activity', 'admissions', 'attendances', and 'consultations'. I reviewed all resulting abstracts myself and retrieved relevant publications. This search was supplemented by personal communication with national experts such as Dr Helen Duncan, Director of the Child and Maternal Health Observatory. In the case of primary care, I enquired more widely about the existence of further grey literature and the possibility of accessing national activity data, which included detailed correspondence with Julia Hippisley-Cox, Professor of Clinical Epidemiology and General Practice at Nottingham University, and Andrew Jackson, Deputy Director, Commissioning, Analysis & Intelligence, Department of Health. This correspondence did not identify relating to national Primary Care data, with the exception of the Qresearch data discussed below. I was also unsuccessful in my attempts to gain access to primary data sources, including the Qresearch dataset.

Primary care

An English study by Qresearch in 2007 (76) showed that, despite the reduction in early years mortality described above, General Practice consultations remain very common in children under 5, particularly among boys. There was a low average consultation rate of below 3 per year during the primary school years before activity increased in early adolescence for girls and mid/late adolescence for males. Based on a sample of over 40 million patient years from 554 GP practices, this study is less comprehensive than the HES data discussed below but provides a reliable guide to age trends, with low risk of systematic bias. Unfortunately, in common with many other datasets, the age bands chosen limit the comparability with data from other settings (see section 2.1 for further discussion of age band analysis).

Emergency and secondary care

All hospital activity in England is recorded by the Trust and submitted to the NHS Information Centre. Although some inconsistencies in the coding quality remain,(77) the resulting Hospital Episode Statistics (HES) dataset provides a rich resource for health service researchers. In 2008, the Department of Health published a report by Hugh Cochrane entitled 'Trends in children and young people's care: Emergency admission statistics 1996/7 – 2006/7'.(78) Covering the ages 0-19, this showed a high number of emergency admissions in infancy which fell rapidly over the first five years. Admissions then remained at a low level during the primary school years before rising steadily in adolescence.

Time trends were analysed in the age groups <1, 1-4, 5-15, 16-19. Over this period, emergency admissions per thousand population remained fairly stable in both the 5-15 and 16-19 groups, while those for younger children and older adults increased slightly. A consistent trend for the 0-19 group as a whole was an increase in the proportion of emergency admissions through the Emergency Department and a corresponding fall in the proportion of admissions referred by GPs. Regarding admitting specialities, the most significant trend was for a greater number of children and young people admitted under the care of ED doctors.

Other authors have linked these changes in emergency admissions to the length of stay. For example, Saxena et al (2009) reported an increased in short-stay unplanned hospital admissions between 1997 and 2006, particularly among very young children.(79) However, there has been no little published research into the cause of attendance at different ages, the relationship between ED activity and health status, or the influence of deprivation on patterns of ED use. The Kennedy report identified the need for further research in this area, reporting concerns that more deprived families were less able to access GP services and consequently relied more on Emergency Department care.(27)

These studies all use national HES data. With comprehensive national coverage, these data should have no risk of sampling bias and low risk of systematic recording bias. Significant concerns have been raised about the quality of some HES data (see section 8.1 for further discussion) – particularly misclassification of diagnostic categories by non-clinical coding staff.(80;81) However, this analysis uses more objective data (e.g. dates of admission/discharge), which are less subject to such misclassification.

Regarding adolescent inpatient activity, the best available English evidence comes from survey data published by Viner in 2001.(29) Excluding activity related to Obstetric care, Mental Health, and Learning Difficulties, he found that total inpatient bed days per 10 000 people increased significantly from 17.0 (SD 7.4) at 12 years to 24.6 (SD 7.7) at 19 years (t=-4.5, P<0.001). Males accounted for more bed days than females in early adolescence but, for males, the number did not increase significantly with age. Female activity increased through adolescence and was significantly greater than males from the age of 17. Data were collected by a survey sent to health authorities and boards across England, Scotland and Wales, with a response rate of 79%. This study successfully demonstrated the volume of adolescent healthcare activity in the UK, but was not intended to provide a detailed analysis of this activity. Despite improvements in the quality of, and access to, Hospital Episode Statistics, no subsequent analyses have been published into adolescent inpatient activity in England within the last decade.

Internationally, there is also a paucity of literature on hospital activity for adolescents, particularly regarding inpatient services. The most relevant published study was performed in the USA by Callahan and Cooper in 2010(82) which compared the number of ambulatory care visits by adolescents (13-18 years) and young adults (19-24 years). Their findings raised particular concern about the insurance coverage and access to care of young adults. Although a similar number of visits were estimated in the two groups (55 million versus 56 million visits annually respectively), data for young adults differed from adolescents in showing a lower proportion of males (30 vs. 46%) and a higher proportion of visits accounted for by black young people. Emergency Department visits also made up a higher proportion of all visits among young adults (20 vs. 14%). Finally, 54% of young adult ambulatory visits were covered by private health insurance, compared to 65% among adolescents. Other US studies have similarly shown the importance of insurance coverage, with lower rates of elective care and higher proportion of emergency department care among non-white and poorer groups who are less likely to have health insurance.(24)

Although, this is a good quality study, with large, very complete datasets, the main purpose of the study was to investigate the association between insurance coverage and healthcare use. Along with the different organisation of care in the USA, this makes it difficult to draw inferences from these data about patterns of health service use in the English NHS.

Inequalities in adolescent healthcare use

Overall, the English NHS performs well for equitable access to healthcare services. A Commonwealth Society study in 2004 found that England showed a significant pro-poor bias in use of primary care services. Of the 22 countries studies, England also showed the smallest pro-rich bias in use of specialist services.(83;84) In another study, England was the only country where low-income respondents reported higher quality of healthcare than those with high incomes.(79) These studies were conducted with identical methodology in each countries and provide the best available data with which to compare inequalities in healthcare activity between countries. However, these surveys were restricted to adults (over 18) and the majority of participants were older adults, again suggesting that their relevance to adolescent health services should be interpreted with caution.

As discussed in section 1.2, the Labour government inequality strategy targeted specific health measures, including immunisation rates, road traffic accidents and teenage conceptions. Inequality in use of health services was not directly measured and has been the subject of less research interest. In 1998, Cooper et al (85) showed that primary care activity was higher in more deprived children and young people but that this difference disappeared when adjusting for perceived health status. Even less effect of socio-economic status was reported by Saxena et al (2002) in a BMJ paper using data from the 1999 Health Survey for England.(86) They found that social class (measured by occupation of the head of household) was not associated with any difference in self-reported health status or use of health services, although there were minor differences between ethnic groups.

Both of these papers used good quality national dataset and standard analysis techniques (weighted mean activity rates and logistic regression) with no obvious significant risk of bias or confounding. However, there is a marked discrepancy between these findings, based on survey data, and more recent publications such as the Marmot review, (37) which are based on much larger datasets and show social gradients across a wide range of health and educational outcomes among children and adolescents. For this reason, trends in healthcare activity, health status and health behaviours by socioeconomic group are analysed in detail in sections 2.5 and 5.5.

1.4 Young people's experience of NHS services

To inform the work of the Children and Young People's Health Outcomes Forum (see section 1.2), the Department of Health recently commissioned the National Children's Bureau (NCB) to perform a rapid review of evidence relating to young people's experience of NHS services in England.(87) This section presents key findings from their review, which was published in 2012, and relates them to the wider policy context.

An important distinction in much of this literature is between patient experience (more objective measures of time waiting to be seen, cleanliness of facilities, etc) and patient satisfaction (a more subjective overall assessment). Patient experience measures are often seen as more useful feedback to providers in how they can improve their service, while satisfaction scores may provide a useful summary measure. However, this from the Picker Institute) than by generalists (e.g. the Kennedy report).

Background

From 2001 to 2011, the English NHS commissioned a large-scale series of national patient surveys. The resources devoted to collecting survey data were matched by political commitment from both main political parties to make the NHS more responsive to patients' needs. Under the Labour government, Lord Darzi identified patient experience alongside clinical effectiveness and patient safety as one of the three pillars of healthcare quality.(88) Through the NHS White Paper (2010)(89) and the subsequent Health and Social Care Act (2012),(60) the coalition government cemented this importance, naming patient experience as one of 5 key outcome domains for which the Secretary of State and local commissioners would be accountable.

Although studies have shown an association between patient satisfaction and better clinical outcomes – for example better quality of life in patient with epilepsy (90) – recent policy has emphasised that a good patient experience should be seen as an important goal in its own right. Sir Ian Kennedy reinforced the importance of this approach for children and young people's services in his 2010 report, suggesting that satisfaction should be the 'single criteria for measuring the quality of the NHS's services for children and young people'(27),and the 2010 NHS White Paper appeared to agree, stating that the principle of direct patient feedback 'is now standard among healthcare systems worldwide'.(89)

Unfortunately, policy makers' aspiration to take the experience of young people and their families as seriously as that of adults is not yet matched by reality, as will be seen in the following paragraphs and in Chapters 3 and 6.

National Children's Bureau review of young people's views about NHS services

The NCB research team searched for evidence from 2007 onwards, using 7 main databases (NCB Child Data, Applied Social Sciences Index and Abstracts (ASSIA), British Nursing Index, Social Care Online, Medline, PsycInfo, and Sociological Abstract). A variety of search terms were used, all of which combined the words children/adolescent/young people with satisfaction/participation/views. The search generated 677 results, of which 112 were deemed to be sufficiently relevant and were included in the review.

Although not a formal systematic review, the authors report a clear systematic search and evaluation strategy. There was therefore low risk of excluding significant published studies, although the potential for selection bias of studies with positive findings remains – both in the published literature and the relatively high number of articles from the unpublished or grey literature.

The authors adopted a rigorous approach to assessing quantitative findings, judging that only 2 studies used sample sizes and methodology from which reliable quantitative findings could be drawn. However, many other studies provided valuable qualitative conclusions.

The rapid review did not analyse any national patient survey reports directly, as no surveys specific to young people were conducted during this period.

Key findings of the review are presented in three groups.

Quantitative studies
With the exception of material from this thesis (see results in section 5.1 and the published version of this paper in Appendix G) only one large-scale quantitative study into children and young people's NHS experience was identified by the NCB. Written by Hopwood and Tallett of the Picker Institute Europe (2011), this recruited 3783 patients aged 8-17 from outpatient settings in 15 hospitals.(91) Along with the findings presented in Chapter 5, this study stands out as using a formal sampling frame, weighting to ensure nationally representative data, and consistent, validated survey methodology.

The majority were positive about their experience, with 96% reporting they had been well or fairly well looked-after. However, responses about several specific aspects of care were less favourable, with 60% reporting insufficient age-appropriate activities while waiting, 57% unsure what would happen when going in for their appointment, a third reporting that they did not fully understand what their doctors had told them, just over a third saying they did not feel fully involved in decisions about their health, and a quarter reporting inadequate attention to their privacy while being treated or examined.

The primary recommendation of the NCB review is that national data are collected on the NHS experience of children and young people and their families, in a way that gives their voice equal weight to that of adult patients.

Key findings from smaller or qualitative studies

The remainder of their review contains a range of evidence from smaller or qualitative studies about young people’s experience and priorities regarding NHS care in England. Although these studies clearly have higher risk of bias and less generalisable findings, in many cases they offer more detailed report of patient views than the larger surveys. Together, they provide a rich insight into young people’s experience, particularly when consistent findings are found across more than one study.

A selection of important themes from this review and the wider international literature are summarised in Table 2. The following paragraphs discuss each theme in the context of international literature. Many of these themes were the subject of extensive consultations during this thesis and are discussed in detail in section 8.5.

Table 2: Key themes from National Children's Bureau review of children and young people's views.

Theme	**Key findings**	**Reference**
Staff	Poor or absent communication from health staff	Gibson 2010 (92) Kelsey 2007 (93)
Staff	Parents and play staff important, particularly for younger children	Aldiss et al 2009 (94) Gibson et al 2010
Involvement in own care	Frequent failure to involved CYP in decisions	Kelsey et al 2007
Transition to adult services	Lack of continuity and joined-up working	Marchant 2007 (95) Kirk 2008 (96) Wray and Maynard 2008 (97)
Mental health	Users of mental health services stigmatised by their peers	Lovett 2011 (98)
Mental health	Views of young people not taken seriously. Difficult to access services	Lavis 2010 (99)
Vulnerable groups		
- Complex needs	The way health services are delivered could be a barrier to achieving aspirations	Marchant et al 2007
- Care leavers	Lack of information, support and guidance	Cafcass 2008(100)
- Additional speech, language or communication needs	Communication often more problematic	Beresford 2007(101) Watson 2007(102) Sloper 2009(103)

Staff factors

These findings echo the importance of provider characteristics, which previous research has shown to be the most important priority of young people.(104-106) This review only covered publication from 2007-2012, but the messages are largely consistent with findings from earlier studies (e.g. Beresford et al 2003.(107)). Although the physical environment was sometimes mentioned, the papers by Gibson et al (2010), Kelsey et al (2007), and Aldiss et al (2009) consistently report that the attitudes and skills of staff are the key determinants of patient satisfaction and good quality care. Internationally, many professionals have reported feeling uncomfortable or lacking confidence in discussing sensitive topics such as sex and substance use with young people.(24) A randomised study with Australian GPs found that a brief training intervention improved both professionals' confidence and young people's rating of consultation quality. (108) A follow-up study showed that this impact was maintained, with ongoing evidence of improvement 5 years later.(109) These two studies stand out as rare examples of rigorous randomised controlled trial methodology being used to assess both short and long term impact of an intervention to improved adolescent health services.

Despite professionals' reservation, a US study by Brown et al (2009)(110) showed that discussion of sensitive topics such as sex and substance misuse was valued by young people and predicted intention to return to follow up. In common with the WHO criteria, the original YW criteria emphasised the importance of 'staff training, attitudes, skills and values', although the detailed criteria related largely to primary and community services rather than hospital care.

A wider issue related to staff is the prevalence of negative attitudes towards young people in general. These were more likely to be mentioned in the context of mental health services (e.g. Lavis et al (2010))(99) but are relevant to all health services. It has been suggested that the issue of wider negative attitudes to adolescents among staff may be more pronounced in England than other countries, reflecting widespread concern among children's charities and advocacy groups that English society in general more negative perceptions of young people. In one survey, 44% of respondents agreed that young people were 'feral',(12) while the campaign group 99percent (111) has highlighted the mismatch between perceptions of young people as likely to be involved in crime and the reality that they are far more likely to be involved in volunteering and community service projects than other age groups.

It should be emphasised that these two surveys were carried out by the charities Barnados and ‘99percent’, essentially for the purposes of national publicity and advocacy work. They were conducted by polling organisations rather than research groups, with little information available on response rates and sampling methodology. The findings should therefore be interpreted with greater caution than the findings of the research studies reviewed previously.

Organisation of care and vulnerable groups

While most studies report good overall impressions of NHS staff, respondents are consistently more critical of issues related to organisation of care, particularly transition to adult services, and the service provided for vulnerable groups. These include young people with specific health needs (e.g. poor mental health, complex needs, communication difficulties) and those with wider needs (e.g. asylum seekers, black and minority ethnic groups, looked after children). Similar findings are reported internationally, although the US literature focuses largely on insurance coverage and access to services.

Involvement and participation

Kelsey et al (2007) reported that 13-16 year olds in hospital recognised clear limits on the context to their involvement in decision-making, particularly when they were very unwell. However, in general they reported high levels of involvement and feeling in charge of their care and valued this as a means to reduce anxiety/fear and improve the overall quality of care.

Similarly, the NCB consultation found that young people valued the opportunity to be involved in decision about services which cater for them – including designing key elements of the services and monitoring the quality of service it provides. Four key elements for young people were

- Being listened to
- Having their recommendations acted on

- Where their advice was not followed, meeting with decision makers to discuss the reasons for this taking place.

Both patient involvement and wider participation of young people in policy development are discussed in more detail in section 1.5.

Young people's priorities and preferences in care

Moules (2009)(112) asked 129 patient aged 9-14 what they felt were the most important aspects of care to them. Key priorities were technical expertise, communication skills of staff and willingness to talk to them directly rather than just their parents, choice/involvement in decisions where appropriate, friendliness and warmth of staff, being treated with respect.

Although several surveys have been adapted for children and young people, the process of adaptation largely concerns the appropriateness of language and the perceived relevance to young people's lives. No research is presented by the NCB which investigates whether young people and/or their families have different priorities or value certain aspects of healthcare differently to adults.

Policy implications

As seen above, young people report a number of consistent weaknesses in NHS services.(92;106;112) The difficulty has been making changes to training and service delivery in order to improve quality. A related ongoing issue has been the lack of meaningful involvement of children and young people, which may motivate providers to address failings, as well as ensuring that interventions are appropriate to the specific context and needs of service users.

1.5 Participation and health engagement

The United Nations Convention on the Rights of the Child (UNCRC)(1989), has been signed by all UN member countries with the exception of the United States of America and Somalia. It states an obligation to allow children to express their views and participate in decisions affecting them.(113) Hart's ladder of participation describes 8 degrees of participation, from the lower levels described as manipulation, decoration or tokenism, up to the higher levels of user-initiated projects, ideally resulting in shared decision making with adults.(114)

Many advocates for child and adolescent health have used human rights perspectives to argue for greater engagement and participation of young people,(115;116) and for better enforcement of the UNCRC as a means to reduce health inequalities.(115) This chapter focuses on research that a participatory approach to services can improve health and the quality of health services. Three themes emerge from the research literature, although there is clearly potential for overlap between them. They are

- promotion of health engagement/involvement
- how to achieve participation in service improvement projects
- the effect of patient participation on clinical outcomes.

Young people's participation in healthcare

The Royal College of Paediatrics and Child Health recently published a review of young people's participation in healthcare.(59) It concluded that

'*The evidence base available suggests that participation is achievable, may take a number of different forms and may result in positive experiences for both young people and staff.'*

Clarity about roles and expectations is highlighted as a key factor in successful projects, along with honesty and realism from the beginning about what can be achieved. In contrast, inadequate resources or support risks the tokenism or decoration described above, and they note that genuine participation is often difficult unless the overall culture of an organisation is responsive to the voice and the needs of young people.

From the research perspective, they found the literature lacking in both extent and quality. Two systematic review by Crawford (2002)(117) and Coad (2006)(118) demonstrate that participation projects are feasible in a wide range of context and often valued by young people and professionals. Both of these reviews were carried out in a rigorous manner, with clear search terms and inclusion/appraisal criteria. However, they of over 300 relevant papers, few had demonstrated significant clinical impact from using a participatory approach, and only a small minority of these studies involved children or young people. Many studies were either very small, of poor quality, or did not use genuinely participatory methods. They emphasise the importance of rigorous future research.

To supplement the peer-reviewed literature, I include below unpublished work by two groups, which has been presented at national conferences (‘Getting Sorted’ and the Young Expert Patients’ Group).

Health engagement and involvement

Wider resonance of the importance of health engagement can be found in many areas of English health policy. Perhaps the most explicit was the Wanless review (2002), which addressed future NHS costs due to an ageing population and increasing sophistication of medical technology.(119) Derek Wanless identified health engagement as the key factor determining whether the health services could continue to provide acceptably high quality care at a price the country could afford. With the foundations of health engagement, especially adoption of a healthy or unhealthy lifestyle largely determined by young adulthood,(24) health engagement of adolescents should be seen as a key outcome of health and health promotion services.

Although intuitively attractive, and particularly appealing to those from a business background such as Wanless, health researchers have found health engagement a difficult area in which to conduct research. Literature searches in this field are limited by a lack of consistency and conceptual clarity, with engagement often used as an umbrella term for a range of health and psychological factors, including knowledge about health and healthy behaviour, the value attributed to good health, and personal agency (a person’s ability to influence their own health). In turn, studies of personal agency incorporate a range of constructs including fatalism, self-efficacy, self-determination and locus of control. Interacting with, and potentially mediating, these effects are personal factors such as self-esteem, impulsivity and deferred gratification (the ability to defer short-term benefit for long-term gain). Lastly, these individual factors should all be placed in the context of wider social and environmental factors, as discussed in section 1.9.

Programmes designed to engage young people in their health have often focussed on developing the skills, knowledge and confidence to manage a long term condition independently. Examples within English settings include the Getting Sorted programme, developed by researchers at Leeds University which runs peer-led workshops for young people aged 12-17 with diabetes or asthma.(120) A similar approach is taken by the Young Expert Patient Programme which provides workshops aiming to give 'young people the skills to improve the management of their condition from both a health and a social perspective.'(121) The peer learning environment is identified by participants as a key part of both programmes' popularity, consistent with the approach described above and recent findings from peer-led health promotion interventions for smoking (122) and bullying.(123)

Although popular with young people, professionals and some commissioners, evaluations of intervention to increase health engagement have often focussed more on the experience of participants than improvement in clinical outcomes. One exception is a series of qualitative studies in children and young people with cancer conducted by Professor Gibson at London South Bank University. One study found that listening to young people and encouraging meaningful participation in decision-making reduced delays in diagnosis and improved psychological outcomes.(124) A further study in 2010 (cited above in section 1.4) showed that involvement of children and adolescents in their care prepared them to make informed health choices and decisions in adulthood.(92)

However, at a time of financial constraints, it has proved difficult to use qualitative results such as these to make an economic case for participation, especially as the benefits may only be realised over many years.

Evidence that engagement and participation of young people improve clinical outcomes

Moving to quantitative research, a Dutch study by De Wit et al in 2007(125) found that range of psychosocial factors, particularly lower social and family functioning, on the Child Health Questionnaire (CHQ-CF87). Similar associations have been found in two prospective, longitudinal studies. (Bryden et al 2001; Hesketh et al 2004)(126;127).

The related concept of self-efficacy has been studied in adolescents with diabetes for many years with an American study by Grossman et al (1987) showing an association between self-efficacy and some aspects of diabetes care.(128) A randomised controlled trial by Anderson et al (2009) showed that a self-management intervention improved quality of life and understanding of diabetes among 310 adult patients with Type 2 diabetes.(129) However, there is less evidence of effective interventions among adolescents.

Health system processes are also important: a systematic review of transition by Crowley et al, 2011, found 4 studies demonstrating a link between high-quality transition programmes and improved subsequent diabetes control.(130) Although again the interventions were not consistently framed in the language of health engagement or adolescent friendly care, the effective approaches included an emphasis on involving young people, promoting autonomy and self-management, and providing care in a way that meets the specific needs of this age group. Similarly, Shaw et al (2006) found clear benefits of a smoother transition on health related quality of life (HRQoL).(131)

Services developed in consultation with young people might be expected to empower patients and deliver a smoother experience of transition to adult services. A review carried out for NHS Kidney Care found wide interest from professionals and young people in this approach, particularly in the areas of cystic fibrosis, rheumatology and renal medicine.(132) They found studies linking improved and dedicated services for young people with a wide range of outcomes, from adherence to medication, preservation of renal transplant and biochemical measures of renal function. More recently, a paper by Harden et al, published in the BMJ in 2012, evaluates the impact of a dedicated clinic and youth worker support programme for young adults with renal disease. Following theses changes to the service, rates of graft failure following kidney transplant in 18-24s fell from 6/9 (67%) from 2000-2006 (pre-intervention), to 0/12 from 2006-10 (post-intervention).(133)

However, even the most successful of these studies have yet to show consistent long term benefits and most did not frame their interventions using a specific adolescent friendly approach. Very little evidence to date has demonstrated a direct improvement in the clinical effectiveness of young people friendly services and this remains an important area for future research. The evidence base may be strengthened with publication of a Cochrane review of transition, which is currently in progress (personal communication, Dominic McCutcheon, London South Bank University).

1.6 Physical, psychological and social transitions during adolescence

This short section introduces a framework for understanding adolescence as a series of linked transition processes. It draws on a review of the literature in a number of related fields, which was published in the Lancet in 2007.

Adolescence as a unique life stage

Understanding of the nature of adolescence continues to evolve, but can be usefully described in terms of biological, psychological, social transitions, all of which continue until at least the mid-twenties.(134;135) Studies have long demonstrated the impact of neuro-endocrine changes and sexual maturation (136;137) but recent findings emphasise that the brain continues to mature for a decade beyond puberty, with continued development of the pre-frontal cortex and expansion of cortical-cortical communication.(134;138)

From a psychological perspective, adolescence is a time when the concept of the self, the ability to understand other’s perspectives, attitudes to risk, and susceptibility to peer influence all undergo major changes.(139) Consistent with brain imaging studies mentioned above, recent findings show that the interaction between risky behaviour and the presence of peers continues to develop throughout adolescence and beyond.(140)

Meanwhile, the nature of modern society is changing the social transition to adulthood, both in the criteria that define adulthood, and in increasing ambivalence about their own feel they are fully adult before their late 20s, linked to later achievement of traditional social markers of adulthood, such as marriage, parenthood, living separately from their own parents and achieving financial independence.(142) In England, a qualitative, longitudinal study of over 100 young people between 1996 and 2006 reported similar themes, with many participants living with their parents and remaining financially dependent well into their twenties and even thirties.(143)

Alongside many other transitions, young people are expected to take responsibility for their own health, start accessing healthcare independently, and, in the case of young people with a long term condition, negotiate the transition from paediatric to adult services. The barriers that young people often face in accessing healthcare include physical and financial issues, embarrassment or lack of knowledge, concerns about stigma, confidentiality, and consent, and deterrence by an inappropriate or unfriendly service.(3;24)

Health services for adolescents can learn from research in a wide range of fields. Subsequent sections provide an overview of key findings from a range of relevant disciplines, including epidemiology (1.6), neuroscience (1.7), and social science and public health (1.8).

1.7 Epidemiology of adolescent health

This section reviews key epidemiological findings related to adolescence. The first part draws on cross-sectional data and discusses the contribution of adolescents to population health. The second section takes a life course approach and reviews the importance of behaviours and habits acquired in adolescence to lifetime health. The third and final section discusses the implications of this evidence for health, care services.

Adolescent epidemiology may be seen as an emerging academic field, with a Medline search using the terms producing few results before 2007 that use national or international data sources. However, it has been a growing field in recent years, with publication of some high quality, widely cited papers – some of which are discussed

Contribution of adolescents to population health

Historically, adolescence has often been seen as the healthiest time of life and health systems have responded by focussing on services for young children and older adults. This section reviews two trends that are increasing the importance of adolescence for population health. Firstly, dramatic reductions in mortality and morbidity among young children have not been matched by trends among adolescents, increasing the adolescent proportion of total disability and deaths. Secondly, the global burden of disease has moved from infectious diseases such as malaria, pneumonia and diarrhoea, towards non-communicable diseases which are heavily influenced by health behaviours acquired in adolescence.

Viner et al (2005) reviewed English mortality data between 1960 and 2000.(28)
Over the 40 year period, they found that standardised mortality in children aged 1-4 fell by around three quarters, from over 80 to just over 20 per 100 000. During the same period, mortality among adolescents showed a smaller decrease, falling among 15-19 years olds from just over 60 to around 40. Consequently, adolescence is now a time of higher mortality than any other period of childhood outside infancy. Although the authors acknowledge some changes in methodology over time, particularly in classification of deaths, there has been universal death registration throughout this period and there appears to be low risk of significant bias in these findings.

They argue that the English NHS, in common with other health systems, has failed to take account of this change, with paediatric training and services still largely built around the post war goals of reducing deaths from infectious disease in early childhood.

These secular trends in England are mirrored in global data. A subsequent paper by Patton et al (2011) used WHO data to investigate 50 year mortality trends in young people aged 10-24 in 50 low-income, middle income and high income countries.(20) Between 1955 and 2004, all-cause mortality in children aged 1-4 decreased by 85-93% compared to a reduction of 68-78% among early adolescents (aged 10-14 years). Mortality among young men aged 15-24 declined by 41-48%, resulting in overall mortality rates in this group becoming two to three times more common than among boys aged 1-4. Mortality in young women saw greater changes than among young men but from 2000 onwards, mortality was similar among women aged 20-24 as girls aged 1-4. The authors argue that this reversal of historical mortality patterns should lead to a corresponding change in global health targets, away from a narrow focus on maternal and early childhood mortality.

Compared to the English mortality data, the data from several countries were much less complete and more subject to changes over the period of the study. However, the consistency of findings across such disparate countries suggests that the main findings are likely to be reliable.

Morbidity data also demonstrate the large contribution of adolescents to the global burden of disease. Gore et al (2011) analysed data from the WHO 2004 Global Burden of Disease Study and found that young people aged 10-24 accounted for 236 million Disability Adjusted Life Years (DALYs), representing 15.5% of DALYs in all age groups. The greatest disease burden resulted from neuropsychiatric disorders (45% of years lost through disability (YLDs), unintentional injuries (12%) and infectious and parasitic diseases (10%).

Importance of adolescent behaviour for lifetime health

As introduced in section 1.1, adolescence should be seen as a critical stage in the life course, which is influenced by antenatal and early years' factors, and in turn has important consequences for adult life and future generations. Sawyer et al (2012) provide an overview of this life course approach in the 2nd Lancet series on adolescent health introduced above.(9)

One well-recognised example is that investments in the physical and mental health of pregnant adolescents can pay significant dividends for the health of their children. The effects are seen globally, although the relative importance of different causes varies widely between and within countries. A range of examples are listed, including viral infections such as rubella and HIV, maternal malnutrition and micronutrient deficiency, psychotropic drugs. Cost-effective interventions are available to address most if not all of these issues, from micronutrient programmes, anti-retroviral drugs to reduce maternal-child transmission of HIV, to the Family Nurse Partnership which reduces intergenerational transfer of conduct disorder and low educational achievement.(144)

Sometimes less widely recognised is the importance of ill-health and behaviours acquired in adolescence for individual lifelong health. In total, the WHO estimates that nearly two thirds of premature deaths and one third of the total disease burden in adults are linked to behaviours or medical conditions in adolescence.(145) Important examples include

- Smoking: two-thirds of adults who have ever smoked regularly report starting before the age of 18.(146) Early age of smoking initiation is associated with a lower chance of quitting as an adult (147;148) and higher death rates from many cancers.(149) Globally, nearly one in five adolescents aged 13-15 smoke tobacco, with recent reductions in high income countries matched by increases in middle income countries such as Indonesia and China.(9)
- Mental health: in US data, 75% of adult mental illness presents before the age of 24, with half presenting by the age of 14.(150)
- Sexual health: globally 45% of newly-acquired HIV infection occurring in 15-24s (151) while in England, the 16-24 age-group reports the highest rate of sexually transmitted infections,(55) with significant consequences in later life, including infertility.
- Other risk factors which track strongly from adolescence to adult life include obesity, (23) excessive alcohol intake (55;152), physical inactivity(55) and hyperlipidaemia.(153)

Despite the importance of adolescence in the emergence of health inequalities,(32) effects at this age clearly cannot be seen in isolation from social determinants at other stages in the life course. Until recently, the evidence base for intervention during adolescence has suffered in comparison with the evidence for early years interventions. However, Heckman (2008) suggests that this is a false choice, arguing that ‘investment at this stage can build on previous achievements or, less efficiently, compensate for adverse early experiences.’(38)

As part of the 2012 Lancet series, Catalano et al reviewed prevention and health promotion interventions and found large numbers of programmes with proven cost-effectiveness for both young children and adolescents.(34) The Nurse Family Partnership pioneered by Olds (144) has been shown to generate lasting benefits for the babies of enrolled mothers with $3.23 dollar recouped for every dollar spent. Similarly, the Life Skills Training programme described by Botvin et al (2006) improves long term outcomes of early adolescents, with even more impressive return of $42.13 for every dollar spent.(154)

The effectiveness of health and social interventions in adolescence has led to some to describe it as a second critical developmental period, complementing the ‘window’ in early development (0-3 years) which is known to have such important consequences for lifelong health and well-being. This finds a parallel in more recent suggestions that adolescence represents a distinct period of brain remodelling, when structures and pathways are laid down which will determine or influence lifelong function. These ideas are comprehensively reviewed in the context of human and animal data in a review by Spear (2000).(155) The next section includes a review of the fast-expanding discipline of adolescent neuroscience and discusses the implications of this work for health and health services.

Implications of epidemiology for healthcare services

As discussed in section 1.1, the majority of previous work developing adolescent friendly services has focussed on primary care and/or sexual health services. The epidemiological evidence suggests that both primary and secondary care have important roles to play in improving adolescent health.

Premature mortality in high-income countries is largely related to lifestyle and behaviour, which are primarily acquired in adolescence,(145;156) with a similar pattern increasingly seen in low and middle income countries. Primary care clearly has a crucial role to play in health promotion and supporting young people to engage better with their health. However, in all countries, secondary care may be increasingly important – both in reducing adolescent morbidity and mortality, and for improving the future health of those with long term conditions.

1.8 Neuroscience perspectives on the adolescent brain

The scope of this thesis is not large enough to review the extensive research into brain development in adolescence, its implications for health, and the many interacting levels of health determinants. Unlike the epidemiology research in section 1.7, this field has been the subject of considerable research for the last two decades and before. This section simply aims to identify some key findings in these disciplines, particularly those related to risk and social influence, which may have important implications for adolescent health services.

New techniques such as functional magnetic resonance imaging (fMRI) have revolutionised study of brain development and function in recent years. A review by Steinberg (2008)(157) identified three main changes in adolescence: firstly in the ratio of grey to white matter in prefrontal areas; secondly an increase in connectivity between prefrontal and other regions; and thirdly an increase in dopamine activity in prefrontal-striatal-limbic pathways. The pre-frontal area is responsible for risk assessment and decision making and continues to mature until at least the mid-twenties while dopamine has been described as the brain's 'pleasure chemical' and increases markedly in early adolescence.

Differential rates of maturation between these systems have been linked to functional differences in behaviour and task processing between adolescents and adults. In one study, adolescents (aged 14-18 years) were just as capable of assessing risk during a simulated driving task as adults (aged 24-29 years) but were uniquely sensitive to social cues, taking significantly more risks if they believed their peers were watching them.(158) Simultaneous imaging showed that the differences in adolescent performance were associated with distinct patterns of brain activation, particularly affecting the prefrontal cortex and dopamine systems. Bringing data from imaging and task performance together, they suggest that mid-adolescence is typically marked by a mismatch between a fully mature reward-stimulation system and an executive control system which is still developing.

The relationship between risky health behaviours and performance in laboratory tasks is taking is a normative and ‘healthy’ part of adolescence, mimicking the novelty-seeking and risk-taking behaviour seen around puberty in rats, mice and other mammalian species.(155) Supporting this, one US study found that occasional drug use during adolescence was associated with better adjustment and emotional well-being than either complete abstinence or frequent drug use.(159)

Blakemore (2012) has suggested that the findings from imaging studies and psychological testing reflect the critical changes in social cognition that take place during adolescence.(160) The exquisite sensitivity and importance attached to social influences, often experienced while experimenting and exploring novel environments, mean that risk assessment and decision making may vary widely between different social contexts. Blakemore’s approach supports the importance of peer influence in adolescent behaviour but provides no easy solutions for health promotion to young people.

An article by Steinberg 2003 entitled ‘Less guilty by reason of adolescence’ explored the implications of adolescent neuroscience for criminal justice systems.(161). However, the suggestion that young people in their mid or late teens have diminished responsibility for their actions has proved controversial with law makers and often unpopular with young people themselves who see it as a threat to their autonomy. One clear message is that individual motivation and attitudes among young people should be considered in conjunction with wider determinants of health, which are reviewed in the following section. Despite significant advances in knowledge, is not easy to map straightforward consequences of any of these findings for health policy or services. A recent article by Johnson, Blum and Giedd (2009) reviewed the many difficulties in applying current neuroscience evidence to policy, not least the need to move from a deficit based understanding of the adolescent brain to an appreciation of both strengths and weaknesses.(162)

1.9 Wider determinants of adolescent health

The last two decades have seen much greater recognition of the importance of social determinants of health, with work by Marmot,(163) Kawachi,(164) and many others demonstrating the health effects of socioeconomic status and the social environment. Rather than diminishing the importance of factors such as health engagement (section 1.5) and brain development (section 1.8), socioeconomic determinants interact with, and are mediated by, these individual factors.

The next section review attempts to understand and illustrate these interacting influences, including public health and social science models. As with section 1.8, there is a very extensive literature and the discussion here is limited to research that has been cited or seen as particularly influential or relevant to English health policy.

Recent English policy has drawn heavily on the socio-ecological model proposed by Dahlgren and Whitehead in 1991,(165) particularly for policy related to health inequalities.(66) In this model, there are five layers of health influences, portrayed as a series of concentric arcs with the individual at the centre. These layers represent:

- Age, sex and constitutional factors
- Individual lifestyle factors
- Social community networks
- A range of specific factors related to the individual's life, including education, work environment/unemployment, housing, sanitation and healthcare services
- General socioeconomic, cultural and environmental conditions.

A wide range of similar models can be found in the public health and social science literature, of which the 1994 Bronfenbrenner model (166) is among the best known. Many components of these models are undoubtedly important for adolescent health. Studies have shown convincing links between health/health behaviours and a wide range of individual psychosocial characteristics, influences of peers, family, school and local environment. Less consistent findings have been published about the importance of socioeconomic status (see section 1.2). The difficulty for service providers and policy makers lies in understanding enough of the context in which health-related decisions are made to provide useful support or intervention.

Regarding health promotion, it has been suggested that traditional health promotion campaigns are less likely to be successful among young people than older adults, due both to the importance of context and an aversion to being told what to do. The alternative approach of social marketing was trialled by the Department of Health from

2007-2011, but unfortunately also proved less effective among young people.

Despite the lack of a comprehensive theory of adolescent health behaviour and decision making, there is extensive empirical literature on effective and ineffective approaches to improving young people's health. Consistent with the evidence that young people's brains may function differently to those of adult, this literature includes numerous examples where approaches seen as 'common sense' by adults have proved ineffective or even harmful in practice.

One such campaign, the US anti-crime programme Scared Straight has enrolled over fifty thousand high-risk adolescents since 1978, taking them to meet prison inmates and learn about the consequences of getting involved in crime. For much of this time, no formal evaluation was performed as it was supported by anecdotal evidence and seen as a common sense approach. More recently, reliable studies have found an average 13% increase in crime committed by young people involved in Scared Straight, compared with matched controls who did not take part.(167) There were similar findings in the more comprehensive Cambridge-Somerville Youth Study, which provided high-risk boys aged 10 with intensive professional support and group activities over a 5-year period. When compared with controls many years later, those randomised to receive intensive support as adolescents reported poorer outcomes, including higher rates of death, alcoholism, mental illness and criminal behaviour.(168)

A book by the social psychologist Timothy D Wilson integrates much of the literature around services and policies affecting young people in recent decades, including several examples mentioned above. He concludes that the priority of all both families and professionals should be to avoid a sense of disengagement or alienation from others and wider society. Interventions adopting this approach have often used volunteering to build a sense of belonging to a community and have been effective in improving a wide range of positive outcomes in adolescence, from better school attainment to reduced rates of teenage pregnancy and criminal behaviour.(70) Although largely based on US studies, these findings are highly relevant to the English context and are consistent with the results of the Young People Development Programme discussed in section 1.2.

A less striking but more topical example is the current government policy regarding the health benefits of self-esteem. Regarding young people, the Public Health White Paper(74) states that 'Improving self-esteem and developing positive social norms throughout the school years should be the focus of local strategies.' However, the evidence suggesting that these policy changes will improve health outcomes for young people is inconsistent. There is strong evidence that connection with family and community is protective against a range of poor health outcomes in adolescents,(169) and that social determinants of health are important in adolescence.(32) However, evidence that promoting self-esteem and personal responsibility will improve young people's health is sparse. A recent systematic review found no consistent relationship between higher self-esteem and better health outcomes in adolescence.(170)

1.10 Research priorities, and gaps in existing literature

Drawing on the literature discussed in earlier sections of the chapter, this section aims to summarise key findings, identify some cross-cutting themes and priorities for future research.

- Both the English and international literature have documented consistent, widespread concern about the poor quality of health services for adolescents and the long term adverse health consequences that may result. In response, extensive work has been done to develop quality standards and best-practice guidelines, but there have been few attempts to quantify the scale of the problem at national level or develop an evidence-based national strategy to improve service quality.
- Both activity and survey data show that healthcare activity increases during adolescence. However, there are no good quality published data on time trends in adolescent healthcare activity and there are discrepancies in the published literature about the associations between socioeconomic position, health status and healthcare activity.
- Before 2011, there were no good quality, peer-reviewed, quantitative studies into young people's experience of the NHS. The quantitative study by Hopwood and Tallett (2011)(91) and numerous qualitative studies found many positive report of care overall but reported concerns about many specific issues,

coordination of services (especially during transition to adult services).

- Participation of children and young people in healthcare is a duty under the UNCRC and numerous small studies have demonstrated that it is feasible and often well-received. However, there is little hard evidence that this approach leads to improved clinical outcomes.
- English and international data demonstrate that adolescent mortality and morbidity has decreased much more slowly than that of younger children in recent decades, while behaviours acquired in adolescence have become more important determinants of lifelong health.
- Recent work in neuroscience and social epidemiology also supports greater emphasis on adolescence as a critical period for establishing lifelong health attitudes and behaviour.

Two clear policy priorities stand out. The first is the relative lack of reliable, detailed data on health and healthcare use in adolescence. This gap is seen both in England (27) and internationally.(6) The second is the difficulty in finding or implementing solutions to well-recognised problems. Despite numerous reports into the transition from children's to adult services over the past ten years, many areas report little improvement in young people's experience.(27;73) A key challenge now must to develop interventions and ensure that they are evaluated using reliable, validated tools.

In addressing these priorities, two cross-cutting themes will form an important part of the approach adopted throughout this thesis. Firstly, that promoting healthy decisions by young people must aim to engage and involve the young people themselves if it is to be successful. Although practical implications will differ, the principle can be applied across a wide range of contexts, from healthy teenagers experimenting with alcohol to young patients with diabetes learning to manage their medication. Secondly, that involving young people in designing and monitoring services may be critical to the success of the service: not only because society is changing fast and professionals and other adults often have little understanding of the context in which young people live their lives; but also because such a two-way dialogue with young people may be the best way to create an atmosphere of mutual respect and engagement in which young people learn to take responsibility for their own health.

In presenting this research, I felt that the most logical approach was to start by investigating healthcare use in adolescence, including how socioeconomic factors influence health needs and patterns of accessing care in different settings. Both to complement existing research into primary care services and due to data availability, this analysis is largely restricted to hospital services (Emergency Departments, outpatient and inpatient care). Secondly, I investigate how young people's experience and satisfaction with health services differs from that of older adults and younger children. However, differences in reported patient experience may be accounted for by different expectations and priorities; I therefore go on to investigate whether the healthcare priorities of young adults differs from that of older adults. The last section of this thesis goes on to validate the new standards against data from national patient surveys. The specific research objectives are presented below.

1.11 Research objectives

Consistent with the structure outlined in the introduction, the key research objectives of this thesis are to:

- Characterise adolescent (10-19 years) use of NHS hospital services in England, including inequality effects.
- Analyse the experience and priorities of adolescent patients in national surveys and compare these with other age groups.
- Assess the validity of national standards for adolescent health services in England.

Chapters 2 to 4 describe the methods used to examine each of these research objectives respectively, with findings outlined in Chapters 5 to 7.

METHODS

Chapter 2. Methods used to investigate health service activity throughout childhood and adolescence

Introduction

This section describes the methods used to analyse hospital activity among English adolescents. It includes: analysis of activity by diagnostic chapter and admitting speciality; trends over the past decade; and differences between socioeconomic groups. The primary source of data is Hospital Episode Statistics (HES), which contain information on every episode of clinical care that takes place within NHS hospitals, including inpatient, outpatient and Emergency Department (ED) settings. After successfully completing a 3 day course in data governance and use of the Business Objects software in July 2010, I was able to access HES data directly, using a Citrix portal from the Department of Health network. In this way, I retrieved data on inpatient, outpatient and ED activity for 2008/9.

Direct access to HES data was no longer possible after leaving the Department of Health in March 2011. In order to analyse trends in inpatient activity, I therefore requested inpatient data for the years 1997/8 to 2010/11 from Northgate Information Solutions (171) which has a contract with the Department of Health and the NHS Information Centre to provide customised data tables for research and public health purposes. Partly for reasons of cost, I requested data for ages 1-19 rather than the broader age range of 0-24 I had used when accessing HES data directly. In December

(ChiMat) (172) who suggested a collaboration to investigate HES data further. ChiMat analysts have direct access to HES data and they are currently providing data for ongoing work, which is outside the scope of this thesis.

To place the HES findings in context, a range of publicly available data sources was used, including

- numerous articles identified in the scoping systematic review (see section 2.3)
- published data on primary care activity in England and inpatient activity in Australia and New Zealand,
- Health Survey for England data on socio-economic differences in health and behaviour.

Detailed description of each piece of methodology is given in the five sections below. The findings from the analyses described in this chapter are presented in Chapter 5

2.1 Age trends in inpatient, outpatient and emergency department activity, 2008/9

As noted by numerous researchers (20;33) and policy experts,(6;27) a major barrier to understanding adolescents' use of health services has been aggregation of data into wide age bands (for example 15-34 or 15-44) which obscure specific adolescent needs. I therefore identified the first important step as providing an overview of hospital activity by single year age cohorts, analysing males and females separately. As described above, I used the Department of Health Citrix portal to access 2008-9 HES data directly (the most recent year for which full data were available at the time). For comparison, published data from Qresearch on General Practice consultations in 2007 were used.(76)

Following convention, outpatient activity was assessed by the number of clinic appointments, and ED activity was assessed using attendances. For inpatient activity, a range of indicators is sometimes used, including bed days, spells of care, and Finished Consultant Episodes (FCEs). An FCE is defined as a 'continuous period of admitted patient care under one consultant within one healthcare provider' (81) while a spell is contain several episodes of care between admission to hospital and discharge For simplicity, I used a single measure, selecting FCEs as the most widely used indicator.

FCEs are the standard unit of inpatient activity within HES data, whether for statistical analysis of service use,(81) costs,(173) or clinical review.(174) They also allow international comparisons, as they match separations recorded in Australian and New Zealand data. They are therefore the most logical starting point for analysis of HES data. For a more complete analysis of inpatient activity it would be useful to repeat the analyses using two alternative indicators: bed days and inpatient spells. Bed days provide useful information for service planning and cost analysis but are influenced by provider factors (e.g. time waiting in hospital for investigations to be performed), while spells are also influenced by the degree of care coordination between different medical teams and are defined differently between countries. These further analyses were beyond the scope of this thesis.

Having obtained the activity data, mid-year population estimates for 2008 were then accessed via the Office for National Statistics (ONS). Dividing activity by the denominator population allowed calculation of the number of care episodes per thousand population, both for single years and quinary age bands (10-14, 15-19, 20-24). The ratios of activity rates between males and females at different ages were also calculated.

2.2 Analysis of inpatient activity by ICD10 chapter and admitting speciality

For the initial analysis, the percentage of care episodes in 7 selected International Classification of Disease (ICD 10) chapters was calculated, using inpatient data from 2008/9.

On receipt of the data from Northgate Information Solutions in 2012, more systematic analysis was performed using HES data from 2010/11, again using Finished Consultant Episodes (FCEs) as the indicator of activity.

Disease 10 (ICD10) chapter and by admitting speciality. For the analysis of disease classification, all those with missing data for sex or ICD10 chapter were excluded; similarly, for the analysis of admitting speciality, all those with missing data for sex or admitting speciality were excluded.

Data from age 1 to 19 were analysed, with 19 being the upper limit of both the WHO definition of adolescence (10-19)(145) and the National Service Framework for Children and Young People in England (0-19).(46) An important objective of this analysis was to raise awareness of the amount of hospital activity accounted for by adolescents. There has been extensive discussion in the policy and research literature about the demographic transition within mortality rates over the past 50 years. Studies show that in high-income countries, adolescence now has higher rates of mortality than any other period of childhood outside infancy.(18;28)

The data relating to disease category were analysed in two complementary ways, both using the International Classification of Disease version 10 (ICD10). Firstly data were disaggregated for each ICD10 chapter, aggregating activity within quinary age bands in order to produce more robust figures for the less common disease groups. Secondly, data were presented by single-year cohorts for the major diagnostic chapters, using a threshold of ICD10 chapters that accounted for approximately 5% or more of activity in at least one age group.

Inpatient data were also analysed by admitting speciality, showing the proportion of activity in each speciality during adolescence.

2.3 Scoping review of national trends in adolescent inpatient activity

A scoping review was performed with two objectives: firstly, to identify national datasets which could be used as comparators for the analysis of English data; secondly, to allow interpretation of the findings in the context of previous literature.

The Medline search was performed, using the search terms ‘trends’ AND ‘adolescent’ AND ‘inpatient’, which yielded 675 results. Additional searches were also made of international health datasets held by UNICEF,(175) the WHO,(176) the World

Bank,(177) and the European Union,(178) supplemented by national government websites where indicated.

Inclusion criteria were:

- all admissions within a defined population were analysed
- study population included any patients aged 10-19
- more than one year's data.

Using these criteria, 13 studies were identified, including studies from England, New Zealand, Australia, USA, Switzerland and Japan. The two most common reasons for rejection of studies were limitation to a specific disease or subgroup within a population, or a cross-sectional study which did not allow analysis of time trends. Note that the Department of Health paper discussed in section 1.3 (78) was also excluded as it only contained data on emergency inpatient activity. For six papers, age bands were either not clear or included a minority of adolescents (e.g. 0-14, 15-44). Of the remaining 7 papers (presented in Table 7), no papers presented data grouped into the 10-19 age band, although this could be created by accessing the source data for Australian and New Zealand which is publicly available in 10-14 and 15-19 year bands.

2.4 Time trends in adolescent inpatient activity 1999/2000 – 2009/10

This section compares the findings from English data in 2010/11 (section 2.2) with data from previous years, showing trends in overall activity, specific disease chapters and within different admitting specialities. Due to changes in the coding of HES data for infants and for consistency with other comparisons of child and adolescent health, (18) data from infants were excluded. Mid-year population estimates by age were accessed for the years 1999-2010 from the Office of National Statistics.(179)

Comparison of inpatient activity in adolescence vs. earlier childhood

To complement these findings in mortality data, I compared rates of inpatient activity in adolescence to those in earlier childhood. As noted in section 1.7, there has been considerable recent research interest in comparing mortality rates in adolescence to distorted by high rates of mortality in infancy and a comparison age group of 1-9 years has sometimes been used.(18)

I was interested in performing a parallel analysis to compare rates of inpatient activity in adolescence with those in earlier childhood. However, the average rate for children aged 0-9 is again distorted by high rates of activity among very young children. Activity decreases at a slower rate than mortality (see Figure 5) and is much higher among children aged under 2 than older children.

I therefore felt that children aged 2-9 was the most appropriate comparison group for investigating our hypothesis (adolescents account for more healthcare activity than younger children, excluding extremes of age). However, the group 2-9 is not an established age group in the literature and this approach is open to criticism of being an arbitrary choice. A more comprehensive approach might use sensitivity analysis, performing similar comparisons to a range of comparison groups – e.g. aged 0-9, 1-9, 2-9, 3-9. Although this would be interesting for the future, such work was again beyond the scope of the present thesis.

Analysis

The analysis closely follows the methodology described in section 2.2. Using English data for 1999/2000 to 2010/11, the numbers of inpatient episodes per thousand age-specific population were calculated by age and sex, using both individual years and age-bands of 2-9, 10-19. Activity was then disaggregated into the major ICD10 chapters. This process was repeated for each year’s data from 1999-2010, showing trends in overall activity and major ICD10 chapters for males and females in early (10-14 years) and late (15-19 years) adolescence. Similarly, the change in FCEs between 1999/00-2010/11 was calculated, disaggregating by admitting speciality. For each admitting speciality, the proportion of under-19 activity accounted for by adolescents was calculated. For specialities that see very few patients over the age of 19, this approximate to the proportion of their workload devoted to adolescents.

2.5 Comparison of inpatient activity trends in England, Australia and New Zealand

This section uses the New Zealand and Australian datasets identified in the scoping review to provide international comparisons for the English trends investigated in section 2.4. Using government websites,(180;181) data were accessed for New Zealand 2003/4 to 2008/9 (using Publicly Funded Hospital Discharge data) and Australia 1999/2000 to 2009/10 (using the National Hospital Morbidity Database which includes both public and private hospitals). Contemporary mid-year population estimates by age group were accessed from the same sources. Inpatient activity in both countries was measured in separations. As with FCEs (see above) a separation is defined as a distinct, single episode of inpatient care and the two measures can therefore be directly compared. Furthermore, the Australian and New Zealand data are categorised using identical parameters of age, sex and ICD 10 classification. However, insufficient detail is available on the publicly available websites to compare precise methods of data coding, in particular the training and qualifications of coding staff. There is thus potential for differences in data quality to influence the between-country comparisons. This issue is discussed further in Chapter 8. The total numbers of care episodes included in each analysis were as follows:

England		
1999/00	(ages 1-19)	1 272 445 FCEs
2010/11	(ages 1-19)	1 433 343 FCEs
New Zealand		
2003/4	(aged 10-19)	55 327 separations
2008/9	(ages 10-19)	66 750 separations.
Australia		
1999/00	(ages 10-19)	296 182 separations
2009/10	(ages 10-19)	348 043 separations.

countries, using the earliest and latest data available in each case. Bar charts of disaggregated activity by major ICD10 chapter were created for male and female adolescents in each country. The number of inpatient episodes per thousand population and the percentage change over time were also calculated for each ICD10 chapter.

2.6 Inequalities in inpatient and Emergency Department activity and health 1999/2000 – 2009/10

There are clearly many factors beyond age that influence health and use of healthcare services. For policy purposes, perhaps the most important is socioeconomic status. Under the current reforms, the Coalition Government has introduced a statutory duty to reduce health inequality,(60) and a change towards using health outcomes which are more meaningful to people.(182) Although a full investigation of social determinants of adolescent healthcare use is beyond the scope of this thesis, this section describes the methodology used to investigate patterns and trends in healthcare activity among different socioeconomic groups.

One concern, highlighted by the Kennedy review,(27) is that children and young people from more deprived families face greater barriers in accessing primary care services, leading to disproportionate use of ED. Although I was not able to obtain data on GP consultations by age and social group, I used HES data to show trends in the ratio of ED attendances to inpatient episodes.

Secondly, I calculated age and time trends for the degree of inequality between social groups in inpatient activity, reflected in the mean number of FCEs per thousand population. However, interpretation of these data presents difficulties. As discussed in section 1.3, there are discrepancies in the child/adolescent literature about the relationship between socioeconomic position and health/healthcare use but the most widely cited previous studies by Saxena et al, 2002 (86) and Cooper et al 1998 (85) have shown the importance of analysing health and healthcare activity together. Complex interactions are also noted in the international literature, with work by Dartmouth Atlas group in America finding that more deprived groups suffer poorer between these factors will clearly depend on the context, and is likely to be very different in a system of universal health coverage such as the English NHS.

For comparison, the third part of this section therefore analyses socioeconomic gradients in physical/mental health and healthy lifestyle by age and sex. Drawing on a recent review commissioned by the Department of Health,(87) it addresses three themes arising from consultations with young people for which data were available:

- physical/emotional health state
- having a healthy lifestyle.
- avoiding hospital admission (particularly mentioned by young people with a long term condition).

Assessing inequality in the distribution of health indicators/ inpatient activity across a population

A wide range of techniques has been used to measure and compare population health inequalities. No single measure is universally used; different indicators have particular strengths and weaknesses and may be particularly appropriate in different contexts.

One important distinction is between absolute and relative measures of inequality.(184) This is similar to the distinction made in clinical trials between the absolute and relative risk reduction resulting from an intervention. For example, if poor health was reported by 10% of young people in the most deprived decile and 5% of young people in the least deprived decile, the absolute difference would be 5 percentage points, while the relative measure would show a two fold greater risk of poor health among the more deprived group.

A comprehensive review by Munoz-Arroyo et al (2007)(184) notes that both measures are influenced the overall magnitude of an outcome within a population. For example, a fall in population morbidity/mortality may result in an increased level of relative inequality, alongside a reduction in absolute inequality. They suggest that analysing either measure in isolation may be misleading and I have therefore attempted to use measures of both relative and absolute inequality in this analysis where possible.

A second important distinction in the literature is between measures which focus on the poorest or most disadvantaged groups and techniques which assess the gradient of inequality across the whole population. The first approach sometimes presents the health gap between the target group and a control group – either the most privileged group or the total population. This has the advantage of highlighting the full range of inequality across society, converts readily into simple policy targets, and encourages a focus on the poorest first. In contrast, so-called ‘gradient’ approaches incorporate data from across the whole population distribution. Recent reviews have argued that these techniques are usually preferable,(184) as health gradients are seen throughout the wealth distribution.(185) For example, the Marmot review demonstrated a progressive increase in poor health from social class I to social class V, with a large burden of ill-health in classes III/IV.(37) Just as a policy focus on the very poorest risks neglecting groups in the middle, measuring only the health gap between the poorest and richest groups excludes their data from the analysis.

Where possible, I have attempted to use both gap and gradient measures in order to provide a more comprehensive analysis and facilitate comparisons with previous findings. For example, I start by comparing inpatient activity in the most and least deprived deciles as a first step, before going on to use two techniques which use data from across the whole population.

Firstly, I calculated the trends for the most and least deprived deciles, and subsequently the ratio of inpatient and ED activity between the two groups.

Secondly, I followed Department of Health publications (54) in comparing inpatient activity in the most deprived decile with activity in the overall population. The Department of Health chose this technique as the best way to monitor progress on the stated policy goal: to ensure that ‘the targeted groups and areas (are) keeping up with and exceeding the rate of overall improvement in health in the rest of the population’. From the research perspective, this technique is particularly useful in monitoring progress where poor health outcomes or healthcare activity are not normally distributed within the population, but skewed towards the most deprived group.

Lastly, I followed World Bank guidance in calculating the concentration index of inpatient activity in each group. The main advantage of this technique is that it provides a comprehensive measure of inequality across the full population distribution of deprivation, and allows comparison over time and between countries. (185) Full details of the methods used to calculate concentration indices are presented below.

Using different techniques to analyse the same data provides different perspectives for interpreting the data. For example, healthcare activity in the least deprived decile might be disproportionately influenced by substitution of NHS care for private healthcare among very wealthy families; conversely, activity in the most deprived might be distorted by high numbers of people unregistered with a GP. Depending on the research or policy question being asked, the extreme ends of the distribution may be of great interest (for example, investigating healthcare access among children from homeless or asylum seeking families) or may exaggerate population-wide trends.

Use of different techniques also provides a means of checking the robustness of the findings. Just as sensitivity analysis tests how robust a model's findings are to changes in the inputs, (as discussed above), demonstrating similar findings with different methods increases the confidence that the results are genuine and not a chance result due to a specific feature of the technique used.

Emergency Department/Inpatient analysis

The initial analysis used 2008/9 data on children and young people aged 1-25 obtained directly from the HES database.

The objectives were to investigate the effect of area socioeconomic status (SES) on:

a) attendance at an ED
b) inpatient activity
c) the ratio of ED to inpatient care.

Deprivation was measured using the Index of Multiple Deprivation (IMD).(186). The index is based on 38 separate indicators within seven distinct domains of deprivation (income, employment, health, education, barriers to housing and services, living environment, crime). This overall measure of multiple deprivation has been calculated for every Lower layer Super Output Area (LSOA) in England. ED attendance and the ratio of ED attendance to inpatient care episodes were analysed by age, sex, and Index of Multiple Deprivation (IMD) decile. Chi squared tests were used to compare differences between the most deprived and least deprived deciles (IMD10 and IMD1).

Department of Health method

Inpatient activity was analysed using Finished Consultant Episodes, defined as a 'continuous period of admitted patient care under one consultant within one healthcare provider'.(187).Total FCEs were aggregated into 5 age bands (<1, 1-4, 5-9, 10-14, 15-19). Analysis of socio-economic status used the Index of Multiple Deprivation decile, derived from the patient's postcode.

Following Department of Health publications,(66) I compared absolute and relative differences in activity between the most deprived 10% and the remainder of the population. Activity rates per thousand were calculated by dividing total FCEs by the mid-year population estimates at national level. To allow for the higher proportion of young children living in more deprived areas, the proportion of inpatient activity in each IMD decile was adjusted for the proportion of age-specific population within that decile. This was done by linking the estimated population in each age band and IMD scores for each Medium Super Output Area (MSOA), using data accessed from the Office of National Statistics.(179) Using 2010 data, the 6781 MSOAs in England were ranked according to mean IMD score and divided into deciles, each of which represented contained 674-681 MSOAs and represented 10% of the overall population. The total national population aged 0-4, 5-9, 10-14 and 15-19 was calculated for each deprivation decile. Age-standardization of HES data was performed using SPSS, Version 18 (PASW Statistics 18, Rel, 18.0.0. 2009. Chicago: SPSS Inc).

From the resulting data, I firstly calculated the mean number of FCEs in the overall population and the most deprived decile. I then calculated relative and absolute differences in the mean number of FCEs between the most deprived 10% and remaining 90%. As above, z scores and t tests respectively were used to calculate the significance of these differences.

Concentration indices (World Bank method)

Concentration indices summarise the information displayed in concentration curves. The most well- known example of a concentration index is the Gini coefficient of income distribution which can be derived from the Lorenz curve of income distribution.(188;189)

Figure 1: Example of concentration curve.

Figure reproduced from World Bank.(188)

The Gini coefficient is equal to twice the area between the two lines. If incomes were distributed equally throughout a population, then the poorest 10% would receive 10% of total income, the poorest 20% would receive 20%, and so on. In this situation, the Lorenz curve (B) would be identical to the reference line A and the Gini coefficient would be zero. Conversely, if one person earned all the income within a country then the Lorenz curve would follow the x axis until it approached 100% of population share and the Gini coefficient would approach 1.

The following section describes how grouped data can be used to derive concentration curves and concentration indices for health outcomes. In this case, the population is ranked by IMD decile, starting with the most deprived group. Unlike income, health that lies above the reference line, and a negative value for the concentration index.

The calculation follows standard World Bank methodology(190) The three components of the formula are:

- the cumulative percentage of the sample ranked by economic status (P). Note that following the standardisation described above, this will be in deciles.
- the cumulative proportion of healthcare activity accounted for by group P. This is denoted L(P) in Figure 2 (below).
- The number of socioeconomic groups (T). For data grouped by decile, T=10.

These are illustrated by the concentration curve in Figure 2

Figure 2: Use of grouped data points to plot a concentration curve

Figure reproduced from Wagstaff (2002)(191)

The concentration index could then be created for each group, using the formula

$$C = (p1L2 - p2L1) + (p2L3 - p3L2) + \ldots + (p\mathrm{T}\text{-}1L\mathrm{T} - p\mathrm{T}L\mathrm{T}\text{-}1)$$

By calculating the variances of each data point in the concentration curve, it is then possible to calculate the standard error of each concentration index. Full details of the formulae used to calculate the concentration indices and their standard errors have been published previously by Kakwani et al (1997)(192) and have subsequently been extensively used by the World Bank. (193). An extract containing the relevant formulae is presented in Appendix A

Using these formulae, the concentration indices and their standard errors were calculated for inpatient activity in 1999/2000 and 2009/10, separating by age and sex. As above, the activity rates in each decile were standardised to match the age distribution in the overall population.

A total of 3 618 001 inpatient episodes were analysed:

- 1999/2000: age 0-4= 945 286; age 5-9 = 271991; age 10-14 = 235 656; age 15-19 = 390 929
- 2009/10: age 0-4 = 778 729; age 5-9 = 264932; age 10-14 = 251 972; age 15-19 = 478 506).

Health Survey for England analysis

Data

These data were used to investigate the first two of the themes identified above (physical and emotional health state, having a healthy lifestyle. I selected five indicators from the Health Survey for England (HSE) which related to these themes. Criteria were selected on the basis of face validity and availability of comparable national data from 1999 and 2009 in a format that could be disaggregated by age and socio-economic status.

These selected indicators were:

- general health (self or parent reported)
- self-reported symptoms of poor mental health
- presence of a long-standing illness
- obesity
- smoking.

As introduced in section 1.3, the most thorough analysis of health inequalities among English children was published by Saxena et al in 2002.(86) They concluded that:

1. ‘Children's self reported health status and use of health services did not vary by social class’
2. ‘Self reported health status rather than socioeconomic status or ethnicity is the best predictor of use of primary and secondary services’.

The discrepancy between the first statement and preliminary analysis of activity data (see Chapter 5.1-5.3) led me to examine detailed trends in English healthcare activity among different social groups over the past decade. Furthermore, the strong relationship between health status and healthcare activity, reinforced in the second statement, suggested that it would be necessary to examine parallel trends in both health status and healthcare activity in order to interpret the activity findings.

Regarding health status, the use of numerous health indicators provides a more reliable guide to health inequality trends over time than using a single indicator, especially given the limitations of each indicator when used in isolation.

Self-reported health is a stable, validated measure of overall health, in both adults and young people (194) but is clearly a subjective measure. Indicators relating to mental health (General Health Questionnaire score), the presence of a long term condition, and smoking are more objective but still subject to reporting bias from participants – whether from different understanding of what constitutes regular smoking/a long term condition, or from lack of honesty in answering the question. In contrast, obesity is assessed using objective measurements and age-validated references, but is subject to lower response rates due to participants who decline to be weighed. This increases the risk of sampling or non-response bias, especially if those who are embarrassed about being overweight are disproportionately represented among those who decline to have their height and weight measured.

Further potential criticism of cigarette smoking and obesity as indicators is the weakness of their immediate relevance to healthcare activity; it is likely that general health status is more strongly associated with healthcare use than lifestyle factors such as smoking. However, as well as providing more objective outcome data than the other indicators, I felt that there were two further reasons for including them in this analysis. Firstly, both obesity rates and smoking have been used as a performance target for preventive health services, both in the general public health strategy and more specifically in inequality strategies. Secondly, smoking and obesity are leading population risk factors for premature mortality and morbidity and are heavily influenced by attitudes and behaviours acquired in adolescence (see discussion in Section 1.7)). Inequality trends in these two indicators therefore have important implications for long-term population and healthcare activity.

Using the UK Data Archive (UKDA), (195) datasets were accessed for 1999 (Study Number 4365) and 2009 (Study Number 6732). For consistency with previous literature on social determinants of health, (9) analysis of five public health indicators included children, adolescents and young adults up to the age of 24. (196)

A total of 9102 participants took part in the surveys, comprising 4651 in 1999 (1354 Males (M), 1284 females (F) aged 0-12; 450M, 424F aged 13-16; 531M, 617 F aged 17-24) and 4451 in 2009 (1579M, 1443F aged 0-12; 480M, 489F aged 13-16, 215M, 236F aged 17-24).

Indicators

In the Health Survey for England (HSE), respondents/parents/carers were asked to assess general health using 5 Likert items, which I aggregated to create a binary outcome (very good/good versus fair/bad/very bad). The General Household Questionnaire (GHQ) 12 (197) was used to assess emotional well-being, with a score of 4 or more representing increased risk of poor mental health. The third indicator used the question ‘Do you have a long-standing illness?’ which had a binary response (yes/no). All three questions were addressed to young people themselves from the age of 13. Parents/carers were asked to respond on behalf of children up to the age of 12.

Smoking was assessed using the question ‘Have you ever smoked?’ for respondents aged 8-15 and ‘Do you smoke nowadays?’ for those aged 16-24. Obesity was assessed using height and weight values measured at the time of the interview. Following previous literature, (198) obesity in those aged up to 16 was defined as a z score of weight for height higher than the 95% centile of the reference population. Above the age of 16, a Body Mass Index threshold of greater than 30 kg/m2 was used.

All analyses of HSE data defined socio-economic status by the occupation of the head of household (1999) or household reference person (2009). Tertiles were created containing higher occupations (Classes I, II), intermediate occupations (III non manual and III manual), and lower occupations (IV, V).

Analysis

All analyses produced nationally representative results by using weighting to adjust for potential bias in sampling or demographic factors. The 2009 HSE survey used a boosted sample of under 16s and therefore separate weighting values for respondents up to this age. In order to make valid comparisons between the surveys, age bands were chosen which analysed respondents under 16 separately, as well as accommodating the fact that young people answered most questions for themselves from the age of 13. The exception was smoking where a specific question was asked of respondents aged 8-15. For this question, 16 year olds from the core sample were analysed together with older participants, while 16 year olds from the boost sample were excluded. Full details of the survey methodology have been previously published.(199)

The proportion of children and young people reporting each adverse health outcome was calculated by socioeconomic status tertile and age band. Analyses were first performed for all respondents together and then for males and females separately. Using the exact difference in proportion method, the mean and standard error were calculated for the difference in each health outcome between the most and least deprived groups. T tests were then used to calculate whether the degree of absolute inequality changed significantly between 1999 and 2009.

Secondly, the relative risk and 95% confidence intervals for poor health between the most and least deprived tertiles were calculated for each health outcome. Trend significance was assessed by calculating the z score of the ratio between 1999 and 2009 relative risks.

Chapter 3. Methods used to investigate young people's experience of the NHS and compare care priorities between young and older adults

3.1 Review of 38 national patient experience surveys 2001-2011
3.2 Analysis of children and young people's experience in selected surveys
3.3 Healthcare experience of young versus older adults in inpatient surveys

Introduction

This chapter describes the methods used to investigate the experience of young people who use the NHS. There has been increasing policy interest in patients' views over the past decade, with regular, national patient surveys. In 2008, Lord Darzi identified patient experience as one of the three core aspects of care quality,(88) and it was included as a distinct domain in the health and social care act, 2012.(60) Sir Ian Kennedy's review suggests that the views of children, young people and their families may be particularly important, although they have received less attention than those of adults in recent years.(27) However, previous literature has largely been restricted to qualitative studies or users of a specific service (see section 1.4). In contrast, this chapter uses quantitative analysis of national-level data.

Section 3.1 explores the extent to which the voice of children and young people has been represented in national surveys over the past decade while section 3.2 investigates how young people's responses compare to those of older adults. The third section describes the methodology used for exploring whether young people value different aspects of healthcare quality more highly than other age groups.

All sections use secondary analysis of anonymised data, for which no ethical approval was necessary. Results of analyses described in this chapter are presented in Chapter 6.

Survey selection

I undertook a review of 38 national surveys, comparing the inclusion and experience of children and young people (<24) with those of older adults (25+) over the last 10 years. NHS surveys were identified through '*Liberating the NHS. Transparency in outcomes – a framework for the NHS',(182)* which reported 38 national surveys that were completed or underway in the period 2001-2011. Data or reports from these surveys were accessed via the websites of the Care Quality Commission,(200) the GP Patient Survey,(201) or the Department of Health.(202)

I recorded the number of times that each type of survey had been undertaken. For the most recent example of each survey, I compared the year, sample size, age range of subjects, and age bands for adolescents and young adults in the published reports. This information is presented in Table 3 and was the basis of the methodology used subsequently in this chapter.

Table 3: Characteristics of national patient experience surveys. England, 2001-2011.

Name of survey	Most recent year data available	Number of times survey undertaken	Number of completed questionnaires in most recent survey.	Age of subjects	Age bands of young adult in published results.
Adult Inpatient	2009	8	69 348	16+	16-35
Adult Outpatient	2009	3	72 446	16+	16-35
Adult Emergency Department	2008	3	49 646	16+	16-35
General Practice	2009/10	3	2 169 718	18+	18-24
PCT Residents Registered with a GP	2007/8	5	Approx 10 000	16+	16-35
Independent Sector Treatment Centre	2008/9	3	Approx 14 000	16+	16-35
Young Patient	2004	1	62 276	0-19	12-14, 15-17, 18-19
Community Mental Health Services	2010	7	17 199	16+	16-35
Mental Health Inpatients	2009	1	7 527	16+	16-35
Maternity	2010	2	25 363	16+	16-18, 19-24
Ambulance	2008	2	Approx 4 000	16+	16-35

3.2 Analysis of children and young people's experience in selected surveys

Findings from section 3.1 allowed investigation of young people's experience in different NHS settings. Primary, inpatient and Emergency Department (ED) care are 3 major areas of concern in recent policy debates.(27;203;204) I therefore used the most recent surveys in these areas to analyse young people's experience in more depth.

1 Emergency Department Survey 2008: the dataset with 5 standard age bands (16-35, 36-50, 51-65, 66-80, 81+) can be accessed via the UK Data Archive (UKDA),(195) Study Number 6329). For this analysis, I used a modified dataset with the lower age band subdivided into four bands (16-19, 20-24, 25-29, 30-35), provided to the author by the Picker Institute Europe (205) Further details of the survey methodology have been published previously.(206)
2 Inpatient Survey 2009: the dataset with 5 standard age bands can be accessed via the UKDA (Study Number 6503). Again, I used a dataset with subdivided lower age bands provided by the Picker Institute and survey details have been published previously. (207)
3 GP Patient Survey 2009/10: report was accessed via the GP patient survey website.(201)

One survey included data on patients under 16: the Young Patient Survey 2004, which was confined to inpatient and day care. I compared findings to those from the equivalent questions in the Adult Inpatient Survey from the same year.

4. Young Patient Survey 2004: accessed via the UKDA (Study Number 5168), details of methodology available in the survey report. (208)
5. Adult Inpatient Survey, 2004: accessed via the UKDA (Study Number 5167), details of methodology available in the survey report.(209)

Patient experience questions

For each survey, I analysed up to 4 questions:

- feeling involved in care
- having confidence and trust in the doctors
- being treated with respect and dignity
- overall satisfaction with care.

The wording of questions differed minimally between questionnaires. All questionnaires used Likert items with a range of responses from most positive to least positive experience. For this analysis, I converted each of these items to a binary outcome (positive/not positive experience of care). The wording of the questions and the Likert items used are presented in Table 19 (section 6.2).

Analysis

The analyses used for each survey are described below.

Adult Emergency Department Survey (2008) and Adult Inpatient Survey (2008/9).
Logistic regression was used to calculate odds ratios for the four questions above by age band, using over 25s as the reference group. Odds ratios with 95% confidence intervals and p values were calculated unadjusted, and then adjusted for the presence of a long term condition. Results were stratified by sex. Analyses were undertaken using SPSS, Version 18 (PASW Statistics 18, Rel, 18.0.0. 2009. Chicago: SPSS Inc).

Young Patient Survey (2004) & Adult Inpatient Survey (2004)
SPSS was used to calculate the proportion of positive responses to the four questions above for 3 groups: children (0-11 years) and adolescents (12-17 years) from the young patient survey, and adult subjects (all 16+) from the adult inpatient survey. Odds ratios with 95% confidence intervals and p values were then calculated by age group, using adult patients as the reference group. Results were stratified by sex

Although the YPS included a small number of subjects aged 18-19, it was designed to investigate views of under 17s and I therefore excluded 18 -19 year old patients from the analysis. For the question about perceived involvement in care, I analysed only responses by the young person or jointly by the young person and parent/carer. For the on behalf of the young person.

GP Patient Survey (2009/10)

The commentary report and technical annex were accessed via the GP patient survey website. These report summary data by age band which allowed the calculation of odds ratios for 3 of the above questions. Data available did not allow stratification by sex, or adjustment for the presence of a long term condition as was done in the other two surveys.

3.3 Healthcare experience and priorities of young versus older adults in inpatient surveys

This section presents further methods used to investigate inpatient survey data. The two specific aims are:

1. To compare the scores of young and older adults across 8 key domains of inpatient experience.
2. To compare the importance of different healthcare domains to young and older people, using the correlation between these scores and overall care rating.

Origins of methodology

As described above, the methods in section 3.2 rely on questions identified as particularly important to young people from previous published literature. However, there is potential for this approach to focus excessively on negative aspects of young people's experience and I decided to extend the analysis with a broader comparison of young and older people's experience. With over eighty questionnaire items in some surveys, it was not practical to use every individual question. Previous work by Dr Steve Sizmur, senior statistician at the Picker Institute Europe, had combined related questions to create a number of core patient experience domains.(210) For example, all the questions related to doctors' communications skills and attitude were combined to give an overall experience score for interaction with doctors. These domains were then ranked in order of importance, using the patient-level correlation between each domain score and the overall care rating. This process identified 7 key domains which correlated most strongly with overall satisfaction. For this analysis, scores for privacy were also

Use of domains scores provides a simple but broad way to compare the experience of young and older adults. Again following previous publications by the Picker Institute,(210) we hypothesized that, with large enough sample sizes, this approach of using correlation coefficients to assess the importance of different domains would be an interesting way to compare the relative priorities of different patient groups. This methodology could only be used to compare young and older adults. As shown earlier in Table 3, we found no recent survey data relating to children under the age of 16 and domain scores were not available for the 2004 survey.

Data

We used data from the 2010 Inpatient Survey which included 161 acute and specialist NHS trusts in England. It was undertaken by the Picker Institute Europe on behalf of the Care Quality Commission. Further details of sampling, questionnaire items and domain scores are available from previous Picker Institute publications. (210;211)

Analysis

As described on page 8 (Role of the candidate) this work was done in collaboration with Dr Steve Sizmur, senior statistician at the Picker Institute Europe. The original idea for the study was mine and I drafted the article, performed all statistical tests and created all the tables and figures. However, the calculation of domain scores and correlation coefficients that are described in the following two paragraphs were performed by Dr Sizmur.

Analyses were stratified by gender and age (16-24, 25+). Data analysis was conducted using IBM SPSS version 19. Firstly, case-level scores were calculated for overall rating of care, the principal domains of care previously identified (210) (consistency, respect, involvement, nursing, doctors, pain control, cleanliness), and an additional domain of privacy in order to allow comparison with the previous section and wider adolescent literature.(24) All were standardized scores from 100 (most positive) to 0 (least positive). The significance of differences in mean scores between groups was calculated using Student's t test.

Secondly, the SPSSINC HETCOR two-step procedure was used to calculate Pearson correlation coefficients and their standard errors for the correlation between overall rating of care and the 8 domains. The HETCOR procedure gives an identical correlation coefficient to the standard SPSS command but also produces standard error estimates. The significance of differences in correlation coefficients by age and sex were assessed using Fisher's r to z transformation.

Chapter 4. Methods for development and validation of *You're Welcome* national quality criteria

4.1 Validation of *You're Welcome* standards in inpatient settings
4.2 Validation of *You're Welcome* standards in the emergency department

Introduction

This chapter describes the methods used to validate the *You're Welcome* standards.

Sections 4.1 and 4.2 describe the process of validating the final criteria, using data from the national surveys introduced in Chapter 3.

4.1 Validation of You're Welcome standards in inpatient settings

Background

With publication of the revised *You're Welcome* criteria in April 2011, England became the first country to have comprehensive national standards for all adolescent health services. Unusually for standards produced by a national government, they were endorsed by the World Health Organisation as reflecting best practice. By early 2011, the Department of Health reported that they were being promoted by 81% of English healthcare commissioners, and in use by around 25% of child health services. (4) There is also early evidence of international use, including services in Denmark.

However, in the absence of any evaluation of the impact on clinical outcomes, it became important to obtain data on the validity of *You're Welcome* as a quality improvement tool in secondary care. Data from national patient surveys offered a convenient validation method, especially as they represent quantitative findings from a large, mainstream sample of patients. This complements the qualitative research of the consultation process and previous *You're Welcome* work, which intentionally focused disproportionately on the needs of the most marginalized young people.

This section describes the methods used to validate *YW* as a quality improvement tool in inpatient settings. The results are presented in Chapter 7. This material has been

Sources of data

Drawing again on the surveys in section 3.1 (Table 3), I identified the most recent national surveys for which data were available in the 11-19 age group: the Inpatient Survey (IS) 2009 (ages 16-19) and the Young Patients' Survey (YPS) 2004 (ages 12-17). Both survey were carried out by the Picker Institute Europe (205) on behalf of the Department of Health.

Inpatient Survey (2009): The dataset with five standard age bands was initially accessed via the UK Data Archive (195) (UKDA, study number 6503). On my request, a dataset with sub-divided lower age bands including 16-19, was provided by Steve Sizmur of the Picker Institute Europe.

Participants were recruited from all 162 eligible NHS hospitals in England which provided adult inpatient services in 2009. 3472 young people aged 16-19 were invited to take part, of whom 988 (28.5%) returned useable questionnaires. The numbers of patients by sex, frequency of previous admissions, and the number of valid responses to each questions are presented in Chapter 7. Full details of the survey methodology have been published previously.(207)

Young Patients' Survey (2004): Data were accessed via the UKDA (study number 5168). Patients were sampled from all 150 eligible NHS hospitals in England which delivered inpatient services for children and young people at that time. 125 482 patients were contacted, of whom 62 276 (49.6%) returned a useable questionnaire. 16 706 were aged 12-17 (12-14: 8288; 15-17: 8418), of which the questionnaire was completed by the young person themselves in 7671 cases. The numbers of patients by sex, the presence of a long term condition, and the number of valid responses to each questions are presented in Chapter 7. Full details of methodology have been published previously.(208) The publicly available dataset uses age bands 9-11, 12-14, 15-17, 18-19. Only the 12-17 age groups were analyzed as the majority of the 9-11 band were too young. The few 18-19 year old participants were excluded as the survey was designed for patients aged 0-17. Only responses by the young person themselves were analyzed, excluding responses by a parent/guardian or jointly between the young person and parent/guardian.

Question selection and analysis

I first reviewed 89 questionnaire items from the Young Patients' Survey and 86 from the Inpatient Survey, to select those which clearly matched the content of specific *YW* sub criteria (i.e. those with face validity). A total of 29 questions were selected which are shown in Chapter 7.

I then investigated the association between responses to these 29 questions and the overall rating of care by the young person. For each question, the category response or Likert item was converted into a binary or three-way response as appropriate. A dichotomous outcome for satisfaction was also created (overall rating of excellent, very good or good versus overall rating of fair or poor). Logistic regression was then used to calculate the odds ratio of overall satisfaction in each group, 95% confidence intervals and p values. Following previous analyses of the YPS data, odds ratios were adjusted for sex and for the number of admissions within the last 6 months as a proxy for previous experience of the health service.(212) In the IS, no question about the number of previous admissions is included. Odds ratios were therefore adjusted for the presence of a long term condition instead as an alternative proxy for experience of the health service.

For the final stage, Spearman's rank correlation coefficients were used to calculate the correlation between the overall care rating (using the 5 point Likert scale) and responses to all other questionnaire items (88 in the Young Patients Survey, 85 in the Adult Inpatient Survey). Following the Picker Institute Europe published methodology,(213) the 10 individual questions which best correlated with overall satisfaction in each survey were identified.

Consistent with previously published analyses of these datasets,(213;214) individual level data were used for both the logistic regression and correlation analyses. Analyses were undertaken using SPSS, version 18 (PASW Statistics 18, Rel, 18.0.0. 2009. Chicago:SPSS Inc).

Ethics

No institutional review board approvals were necessary for these secondary analyses of publicly available anonymised data.

4.2 Validation of You're Welcome standards in the Emergency Department

Background

The majority of pilot sites in the project to revise *You're Welcome* focused on the inpatient settings. However, young people, particularly young men from more deprived areas, are known to be frequent users of emergency services. We therefore chose to examine the validity of *You're Welcome* as a quality improvement tool for young adults in Emergency Departments, using data from patients aged 16-24.

Sources of data for validation

Data were analyzed from the 2008 ED survey, which was carried out by the Picker Institute Europe on behalf of the Department of Health. The dataset with five standard age bands was initially accessed via the UK Data Archive (study number 6503). A dataset with sub-divided lower age bands including 16-19, was later provided by Dr Steve Sizmur of the Picker Institute Europe.

Participants were recruited from all 151 eligible NHS hospitals in England providing Emergency Department care. 128 403 patients were invited to take part of whom 49 646 returned useable questionnaires (2189 aged 16-19, 2850 aged 20-24). Children under the age of 16 were not included in the survey. Overall response rates were 35.8% for males and 44.1% for females. The number of patients by sex, presence of a long term condition, and the number of valid responses to each question are presented in the Chapter 7. Further details of the survey methodology have previously been published. (206)

Question selection and analysis

I reviewed 40 questionnaire items to select those which best matched the content of specific *YW* sub criteria (i.e. those with face validity). Of these, 16 questions were selected for analysis.

This process followed the methodology of previously published work (described above) validating the *You're Welcome* criteria for inpatient services. In most cases, the matching between questionnaire items and *YW* criteria was straightforward. For example, *You're Welcome* specifies the training, skills, attitudes and values expected of staff; matched questionnaire items asked whether young people felt that staff communicated clearly, listened to them, inspired confidence and trust, involved them in their care, and treated them with respect and dignity. In some cases, questionnaire items were relevant but did not encompass the full scope of the *YW* criteria. For example, to meet the access criteria fully, services should be accessible by public transport, offer young people consultation alone, allow a preference to be expressed for the gender of staff member, and facilitate access for marginalized groups. However, the questionnaire items on access relate only to waiting times and ease of parking.

I then investigated the association between responses to these 16 questions and the overall rating of care by the young person. For each question, the category response or Likert scale was converted into a binary or three-way response as appropriate. Details of these responses are listed in the results section (Chapter 7). A dichotomous outcome for satisfaction was also created (overall rating of excellent, very good or good versus overall rating of fair, poor or very poor). Logistic regression was then used to calculate the odds ratio of overall satisfaction in each group, 95% confidence intervals and p values. Following previous analysis, odds ratios were adjusted for sex and for the presence of a long term condition as a proxy for previous experience of the health service.

For the final stage, Spearman's rank correlation coefficients were used to calculate the correlation between the overall care rating (using the 6 point Likert scale) and responses to the 39 other questionnaire items. Following the Picker Institute Europe published methodology,(210) the 10 individual questions which best correlated with overall satisfaction in each survey were identified. Analyses were undertaken using SPSS, version 18 (PASW Statistics 18, Rel, 18.0.0. 2009. Chicago:SPSS Inc).

Ethics

No institutional review board approvals were necessary for these secondary analyses of publicly available, anonymised data.

RESULTS

Chapter 5. Characteristics and trends in health service activity throughout childhood and adolescence

5.1 Age trends in inpatient, outpatient and Emergency Department activity
5.2 Analysis of inpatient activity by ICD10 chapter and admitting speciality
5.3 Scoping review of national trends in adolescent inpatient activity
5.4 Time trends in English inpatient activity 1999/2000 – 2009/10
5.5 Comparison of English trends with Australian and New Zealand data
5.6 Inequalities in inpatient and Emergency Department activity and health 1999/2000 – 2009/10

Introduction

This chapter presents results relating to health service activity and inequality. Sections 5.1 to 5.6 correspond to the methods described in Sections 2.1 to 2.6 respectively.

5.1 Age trends in inpatient, outpatient and emergency department activity

This section uses 2008/9 data to provide an overview of health service activity for adolescents, comparing rates of inpatient, outpatient, Emergency Department and primary care use. The methodology is described in section 2.1. Material including these results were presented at the Royal College of Paediatrics and Child Health annual conference in Glasgow, 2012 (see Appendix D)

Table 5 shows that young people account for around 10% of all healthcare activity in inpatient, outpatient and primary care settings, and over 20% of ED activity. Figures 3-5 present activity rates by age for EDs, outpatients and inpatients, respectively.

The number of care episodes per year increases in all settings from early adolescence to the early twenties. In early adolescence, activity in males is greater than, or approximately equal to, that in females; in late adolescence and early adulthood, females account for a much greater proportion of care than males, with the exception of the ED.

The sex difference is particularly marked in Emergency Department attendances between the ages of 10 and 17, where activity diverges for several years before peaking at around the age of 20 at similar levels in males and females. The association between deprivation and increased use of ED services is presented in section 5.6.

Table 4: Healthcare use by age group, England 2008/9.

Setting	**Indicator**	**Age**		
		11-15	**16-19**	**20-24**
Inpatient	Finished consultant episodes	275430	417078	757970
	(% of episodes in all age groups)	(1.7%)	(2.6%)	(4.7%)
	Episodes/year	0.09	0.16	0.21
	M:F	1.06	0.49	0.35
Outpatient	Appointments	2525262	2255934	3292715
	(%)	(3.4%)	(3.0%)	(4.4%
	Appointments/year	0.82	0.84	0.93
	M:F	1.09	0.70	0.47
Emergency Department	Attendances	864316	898061	1211274
	(%)	(6.3%)	(6.5%)	(8.8%)
	Attendances/year	0.28	0.33	0.34
	M:F	1.40	1.10	1.10
General Practice	All consultations	450009	702285	1007431
	(%)	(2.2%)	(3.4%)	(4.9%)
	Consultations/year	1.21	1.89	2.72
	M:F	0.97	0.56	0.37

Figure 3: NHS Emergency Department attendances by age (per thousand) 2008/9.

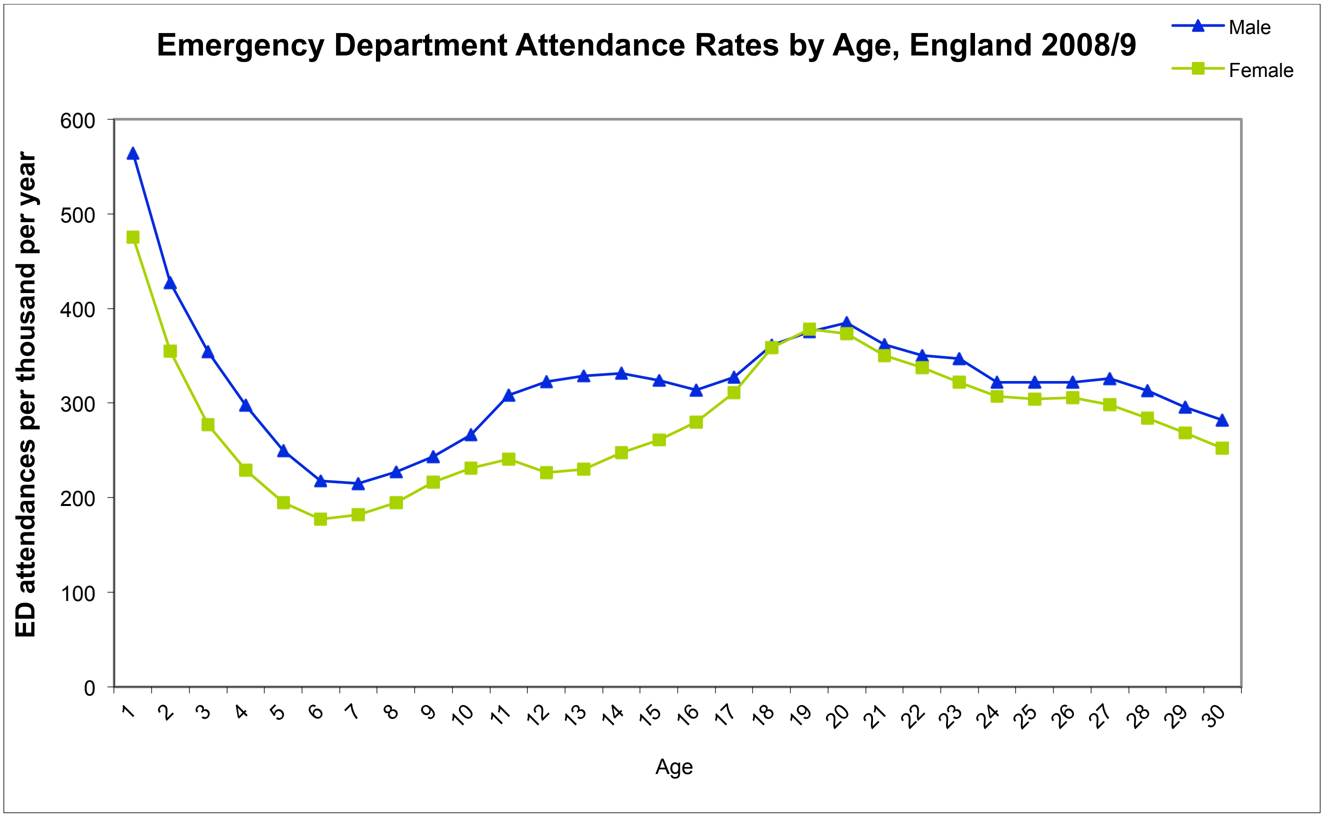
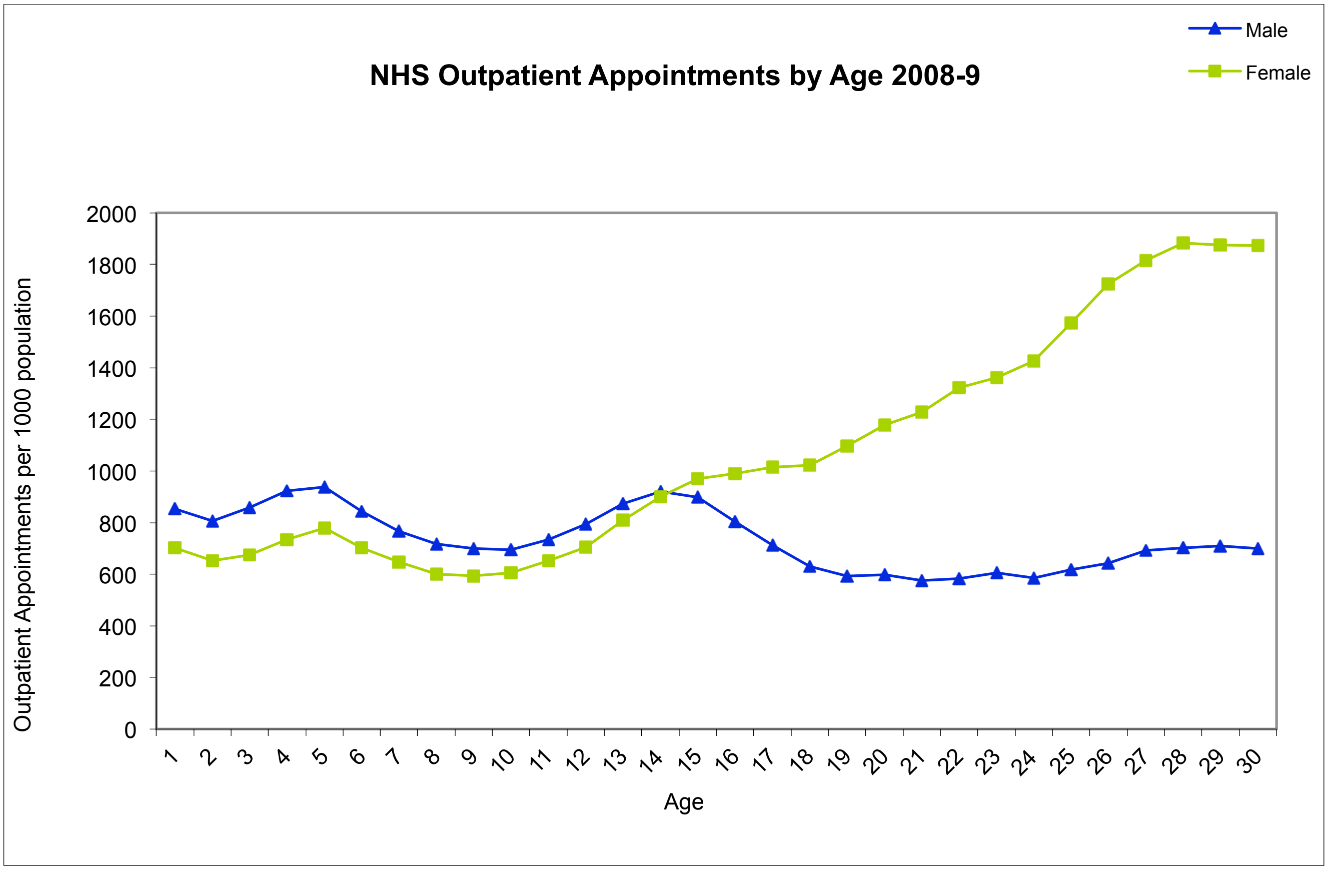


Figure 4: NHS outpatients appointments by age (per thousand) 2008/9.


NHS Outpatient Appointments by Age 2008-9
Male
Female
Outpatient Appointments per 1000 population
2000
1800
1600
1400
1200
1000
800
600
400
200
0
1
2
3
4
5
6
7
8
9
10
11
12
13
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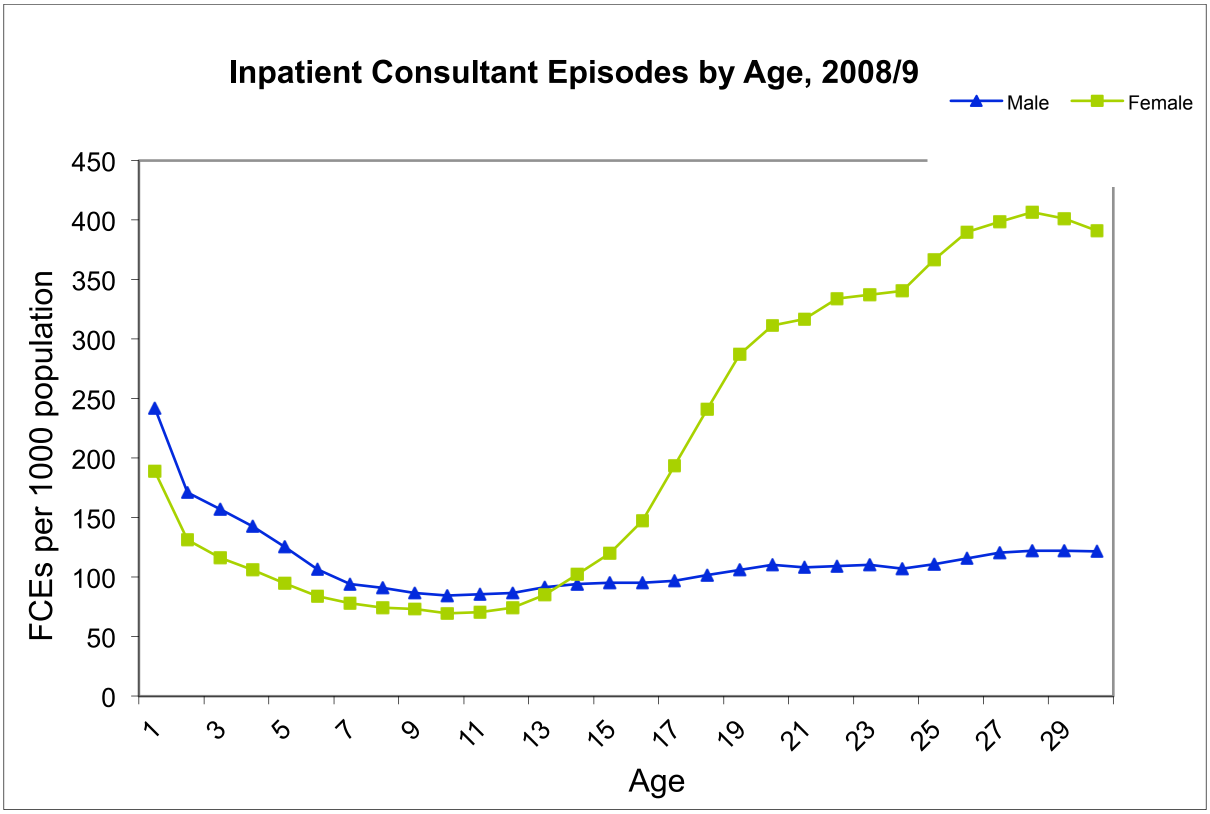
Age

Figure 5: NHS inpatient activity by age (per thousand) 2008/9.



5.2 Analysis of inpatient activity by ICD10 chapter and admitting speciality

Section 5.2 presents 2010/11 English inpatient data, disaggregated for major ICD10 chapters and admitting speciality. Figures 6 and 7 show age trends for activity by major ICD10 chapters.

Female Finished Consultant Episodes (FCEs) per thousand almost quadruple during adolescence, increasing from 70.9 aged 10 to 281.7 aged 19. Much of this increase is in Chapter XV (Pregnancy, childbirth and the puerperium) which contributes 42471 (44.7%) of FCEs among 19 year olds. However, non-pregnancy related activity also more than doubles, from 70.9 to 155.9 FCEs/1000 per year. There are increases in all diagnostic groups shown, including an increase of 123% in Chapter XIX (Injury/poisoning) and an 80% increase in Chapter XI (Digestive system). A much smaller increase from 84.6 to 104.5 FCEs per thousand is seen among males. Much of this change is explained by Chapter XIX (Injuries/poisoning) which increases from 12.5 to 27.4 FCEs per thousand. For both sexes, infectious and respiratory illnesses are less

Figure 6: Male inpatient activity by major ICD10 chapter, England 2010/11.

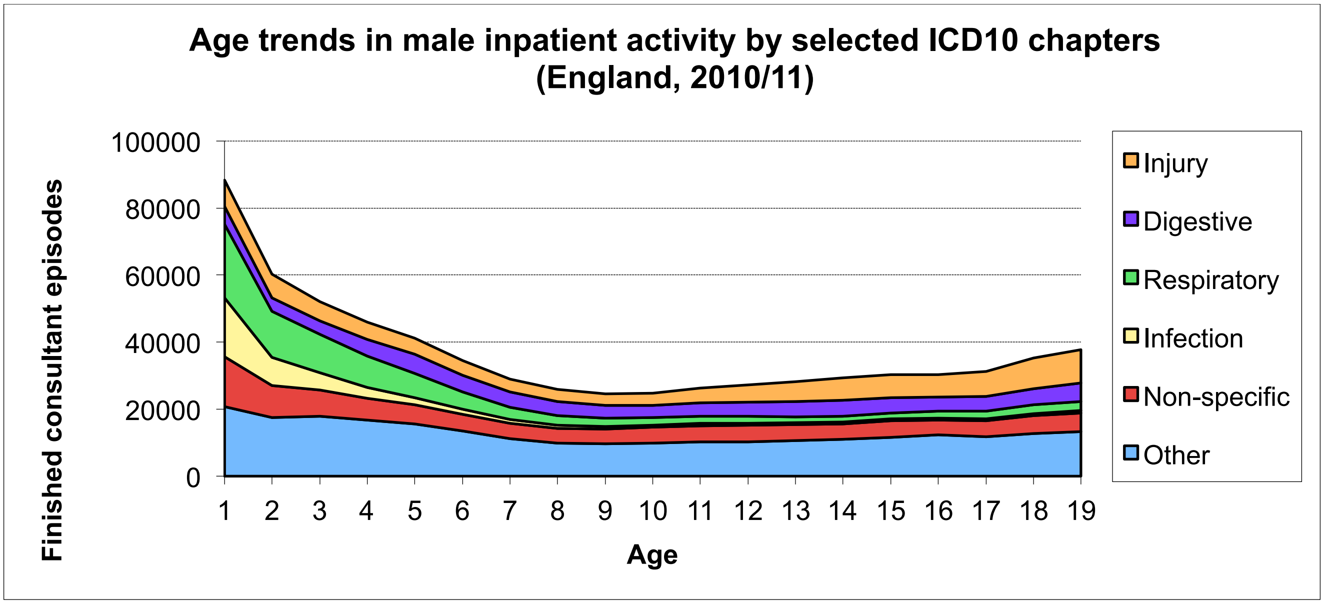
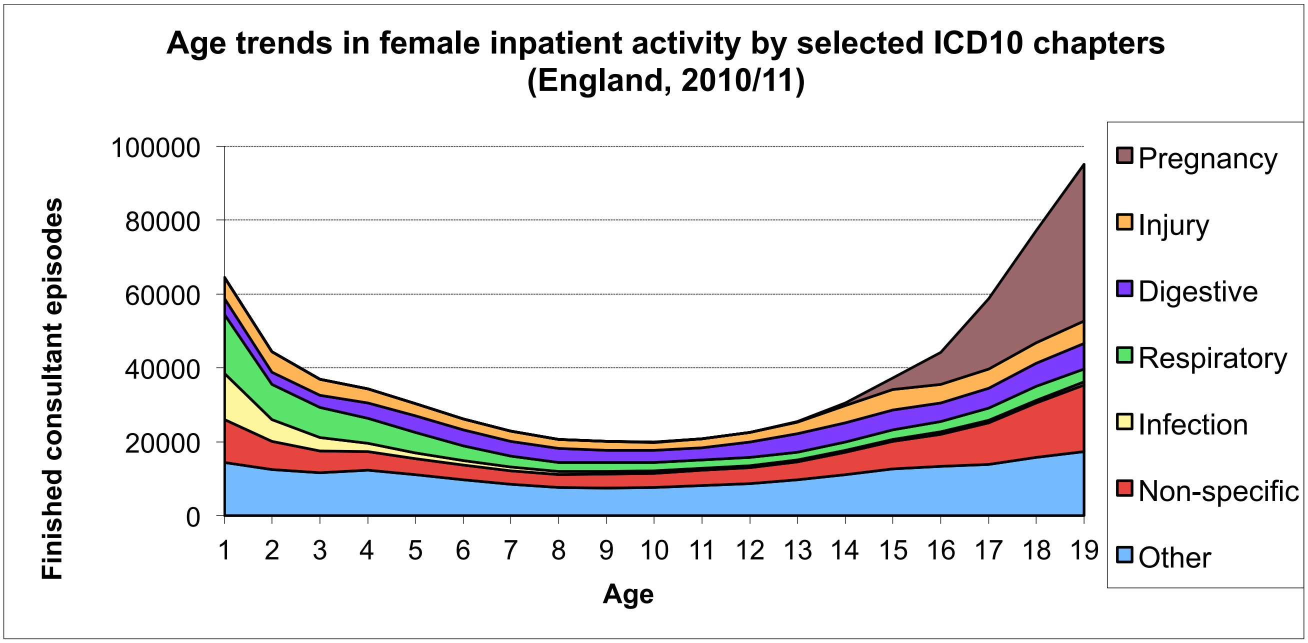


Figure 7: Female inpatient activity by major ICD10 chapter, England 2010/11



Notes

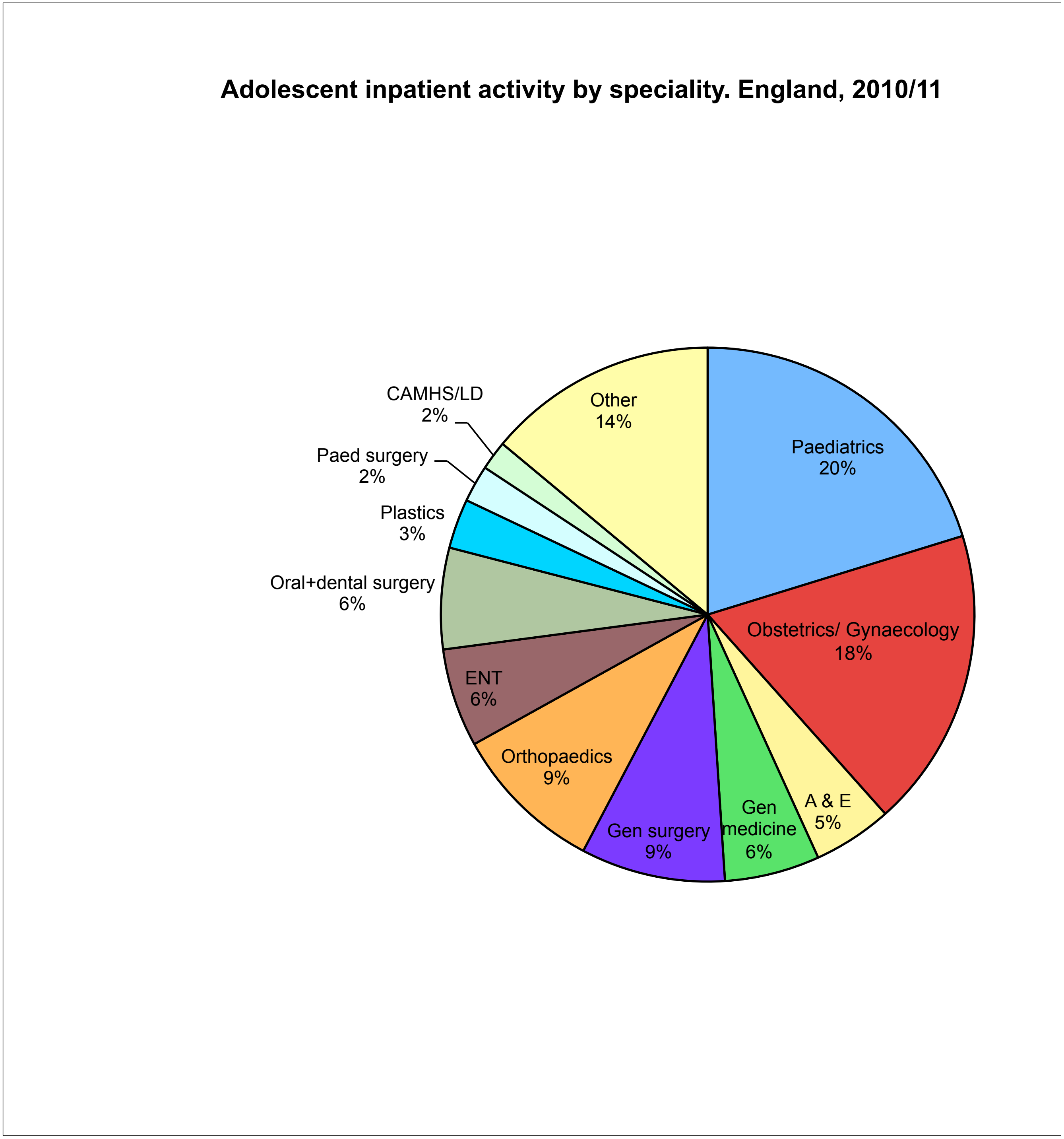
- The full description of ICD10 Chapters is presented in Table xx below
- In Figures 6 and 7, Chapters XVIII and XXI are both displayed as 'non-specific'

Table 5: Legend of ICD10 Chapters.

I. Certain infectious and parasitic diseases
II. Neoplasms
III. Diseases of the Blood and Blood-Forming Organs and Certain Disorders involving the Immune Mechanism
IV. Endocrine, Nutritional, and Metabolic Diseases
V. Mental and Behavioural Disorders
VI. Diseases of the Nervous System
VII. Diseases of the Eye and Adnexa
VIII. Diseases of the Ear and Mastoid Process
IX. Diseases of the Circulatory System
X. Diseases of the Respiratory System
XI. Diseases of the Digestive System
XII. Diseases of the Skin and Subcutaneous Tissue
XIII. Diseases of the Musculoskeletal System and Connective Tissue
XIV. Diseases of the Genitourinary System
XV. Pregnancy, Childbirth, and the Puerperium
XVI. Certain Conditions Originating in the Perinatal Period
XVII. Congenital Malformations, Deformations and Chromosomal Abnormalities
XVIII. Symptoms, Signs and Abnormal Clinical and Laboratory Findings not elsewhere classified
XIX. Injury, Poisoning and Certain Other Consequences of External Causes
XXI. Factors Influencing Health Status and Contact with Health Services

Figure 8 presents data for all adolescents (10-19 years) by admitting speciality. The two largest specialities are Paediatrics and Obstetrics/Gynaecology which together account for 39% of FCEs. The remainder are admitted under a range of different medical and surgical specialities. This diversity has important implications for clinicians and managers who wish to improve services for adolescents in their hospital.

Figure 8: Adolescent inpatient activity by speciality, England, 2010/11.



5.3 Scoping review of national trends in adolescent inpatient activity

Building on the above cross-sectional data presented in sections 5.1. and 5.2, the next three sections investigate time trends in hospital activity for adolescents, and attempt to place English findings in an international context.

Section 5.3 presents the results of the scoping review described in section 2.3. This used the search terms ‘trends’ AND ‘adolescent’ AND ‘inpatient’, resulting in 675 results, of which seven studies met the inclusion criteria. These are shown in Table 7.

Regarding admitting speciality, no studies included national data on inpatient activity in a comparable format to the English data presented in Figure 8.

Regarding disease classification, national data on inpatient adolescent activity were publicly available from 3 countries: the USA, Australia and New Zealand. Although extensive, US data were excluded as they are only available for ages 10-17 and are grouped using a US-specific coding system, - the Clinical Classifications Software (CCS) for ICD-9-CM(215) – rather than ICD10 chapters. However, source data were available for Australia and New Zealand, grouped into 5 year bands (10-14, 15-19, and analyses of these data are presented in chapter 5.5.

Table 6: Studies identified in scoping review.

Study	Country/state	Age bands including adolescents	Dates	Indicator
Jones N, Hardes G, Ryan S, et al. (2008)	New South Wales, Australia	0-14, 15-44*	1998-2004	Separations (care episodes) and bed days
Pracht E, Langland-Orban B. (2007)	Florida, USA	10-14, 15-19	1992-2003	Avoidable admissions
Kanter RK, Moran JR. (2006)	New York State, USA	0-14	1996-2002	Admissions for each Diagnosis Related Group (DRG)
Dharmalingam A, Pool I, Baxendine S, Sceats J. (2004)	New Zealand	5-14, 15-24*	1980-1997	Avoidable hospitalisation
Simpson L, Zodet MW, Chevarley FM, et al (2004)	USA	10-14, 15-17	1987-2001	All hospitalisation
MacFaul R, Werneke U. (2001)	England	5-14	1989-1997	All admissions
Friedman B, Berdahl T, Simpson LA, et al (2011)	USA	10-14, 15-17	2000-2007	Hospital discharge rates

* underlying data accessible in 5 year age

Key findings from the seven studies in Table 7 are presented below

- Jones et al (2008). This Australian study projected a 24% increase in all-age inpatient activity between 2004 and 2017. 0-14s and 15-44s show smaller than average increase in same day separations and a decrease in overnight separations and bed days.(216)
- Pracht et al (2007). This US study found that expansion of public health insurance following the 1997 Balanced Budget Act reduced avoidable admissions in young people. A greater change was seen among 0-14s than 15-19s and other older groups.(217)
- Kanter et al (2006). Total hospitalisation rates for 0-14s in New York State decreased by 2.3% per year between 1996 and 2002. Admissions rates for mental illness increased by 5.5% per year, to account for over 4% of all admissions by 2002.(218)
- Dharmalingam et al (2004) report an increase in avoidable hospitalisations in New Zealand from 1980-1997, during a period of significant policy reforms.(219)
- Simpson et al (2004) studied US national data on child and adolescent care from 1987 to 2001. They found that insurance coverage improved, the site of care shifted toward ambulatory sites, hospital utilisation declined, and expenditures on children as a proportion of total expenditures decreased.(220)
- Macfaul et al (2001) studied English data between 1989 and 1997. Among children aged 0-14, paediatric admissions rose by 19% and surgical admissions fell by 25% with a plateau reached in overall child admissions. By 1997 there were fewer beds in which children stayed for a shorter time and there was more day case surgery.(221)
- Friedman et al (2011). From 2000 to 2007, US national data showed a significant decline in hospital discharges among 15-17s, mainly due to fewer pregnancy related discharges. Some disease groups showed the reverse trends – for example, the rate of admissions for skin infections doubled over this period to 9/10 000. Smaller changes were seen among 10-14s. The authors also report that Medicaid became increasingly important compared to private insurance and there was a trend towards fewer potentially avoidable admissions. They emphasise that there is significant variation in trends by geographical area

income level and insurance coverage.(222)

5.4 Time trends in English inpatient activity 1999/2000 – 2009/10

This section shows the trends in English inpatient activity over an eleven year period. Following the methods described in Chapter 2.4, I start with the summary statistics demonstrating the change in adolescent activity over time and how this compared to activity in younger children. I then present the trends for specific disease groups and specialities.

Table 8 presents the total number of Finished Consultant Episodes in 1999/2000 and 2010/11 for adolescents and children aged 2-9. In 2010/11, adolescents accounted for 731780 FCEs (117.1 per thousand), while those aged 2-9 were responsible for 548779 FCEs (113.6 per thousand). Compared to1999, total adolescent activity increased faster than activity in younger children (increase of 14.2% vs. 7.5%). This was largely due to demographic changes; activity rates per thousand increased slightly faster in the younger age group (13.6% in children aged 2-9; 12.8% in adolescents).

Table 7: Total inpatient episodes ages 2-9 and 10-19, England, 1999/00 and 2010/11.

	Age	1999/2000	2010/11	Ratio 2010/11:1999/2000
Finished Consultant Episodes	2--9	510278	548779	1.075
	10--19	640622	731780	1.142
Mid-year population (thousands)	2--9	5103.3	4830.3	0.947
	10--19	6170.5	6247.7	1.013
FCEs per thousand population	2--9	100.0	113.6	1.136
	10--19	103.8	117.1	1.128

Time trends in inpatient activity by major ICD10 classification

Figure 9 presents trends in adolescent inpatient activity by sex and age (early vs. late adolescence). An increase of 13.0% is seen in overall inpatient activity per thousand in adolescent males (10-19 years). Among the major ICD10 Chapters shown, the greatest increase was in Chapter XI (Digestive system) (+39.8%) and the only decrease was in Chapter XIX (Injury/poisoning) (-1.7%). Overall female activity per thousand also increased by 13.0%, with a greater increase in younger than older adolescents. Total non-pregnancy-related activity increased by 25.1%, including a 48.0% increase in Chapter XI (Digestive system) and a 25.2% increase in Chapter XIX (Injuries/poison). Activity in Chapter XV (Pregnancy, childbirth and puerperium) decreased by 13.3%.

Figure 9: Time trends in inpatient activity by age group, sex and major ICD10 Chapter. England, 1999/2000 to 2010/11

Figure 9: Time trends in inpatient activity by age group, ex and major ICD10 Chapter. England 1999/2000 to 2010/11

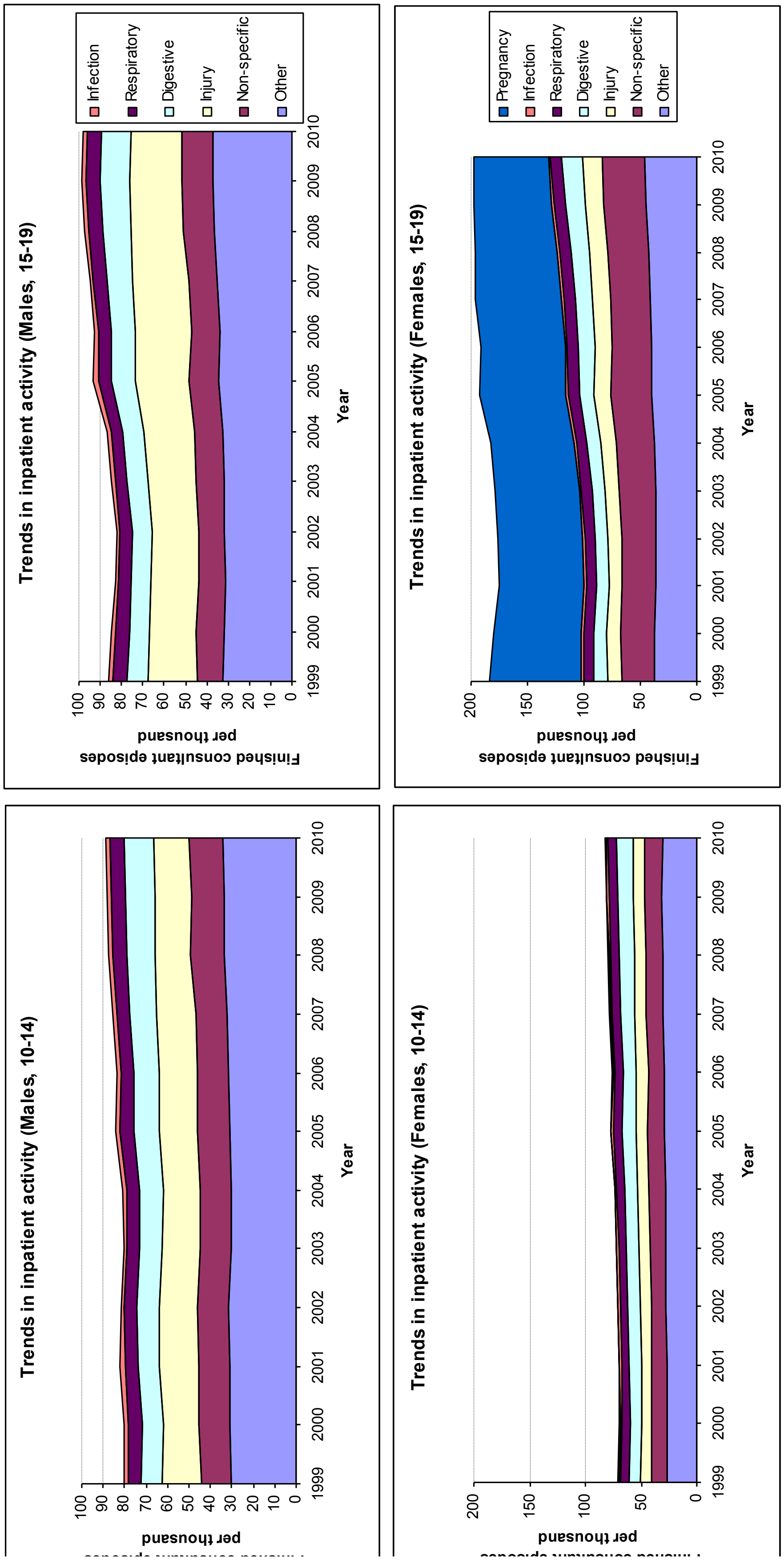


Table 9 presents trends in inpatient activity by admitting speciality, 2010/11. During the period from 1999/2000 to 2010/11, inpatient adolescent activity per thousand increased in the majority of major specialities, including Paediatrics (+47.5%), Accident & Emergency (+317.0%), General Medicine (+15.0%), Oral and dental surgery (+30.7%), Plastic surgery (+6.8%), and Paediatric Surgery (+23.2%). There were decreases in Obstetrics/Gynaecology/Midwifery (-12.0%), General Surgery (-5.0%), Orthopaedics (-6.9%), ENT (-22.3%), and CAMHS/Learning disability (-38.0%).

Table 8: Adjusted adolescent inpatient activity by speciality: current proportion and trends. England, 2010/11.

Speciality	**Percentage change in FCEs per thousand 1999/2000 to 2010/11**	**Proportion of total adolescent activity 2010/11 (%)**
Paediatrics	+47.5	20.2
Obstetrics/Gynaecology/Midwifery	-12.1	18.2
Accident & Emergency	+317.0	4.8
General Medicine	+15.1	5.8
General Surgery	-5.0	8.8
Orthopaedics	-6.9	9.2
ENT	-22.3	6.0
Oral surgery and dentistry	+30.7	6.1
Plastic surgery	+6.8	3.0
Paediatric surgery	+23.2	2.2
CAMHS/LD	-38.0	1.8
Other (2)	+12.2	14.0
Total	+12.8	100.0

Table 10 presents adolescent activity as a proportion of all activity for patients aged 0-19, by speciality. Adolescents make up an increasing proportion of the paediatric workload in the majority of specialities, including an increase from 9.1% to 10.5% of Paediatrics and from 78.0% to 88.5% in Mental Health services. However, a mixed pattern is seen in surgical specialities, with small reductions in the proportion of adolescent activity in ENT and plastic surgery.

Table 9: Proportion of all paediatric activity (0-19 years) accounted for by adolescents (10-19 years) by speciality. England 1999/2000 and 2010/11.

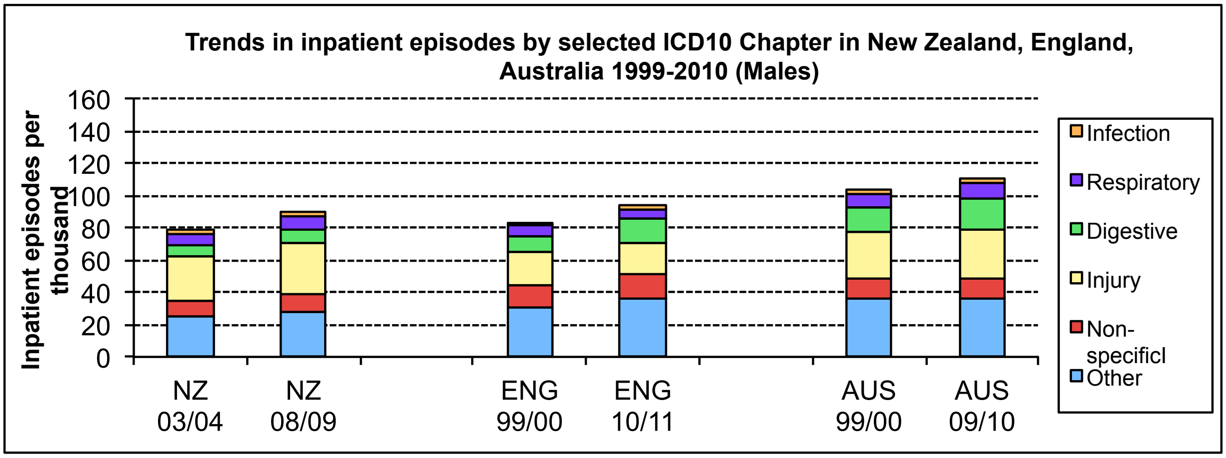
Speciality	Adolescent activity as proportion of all inpatient activity for 0-19s (%)	
	1999/00	2010/11
Paediatrics	9.1	10.5
Obstetrics/Gynaecology/Midwifery	73.6	58.6
Accident & Emergency	73.7	52.0
General Medicine	98.3	99.2
General Surgery	67.8	80.8
Orthopaedics	58.2	63.3
ENT	37.5	36.8
Oral surgery and dentistry	50.8	52.3
Plastic surgery	46.4	45.8
Paediatric surgery	23.8	26.3
CAMHS/LD	78.0	88.5
Total	31.2	29.6

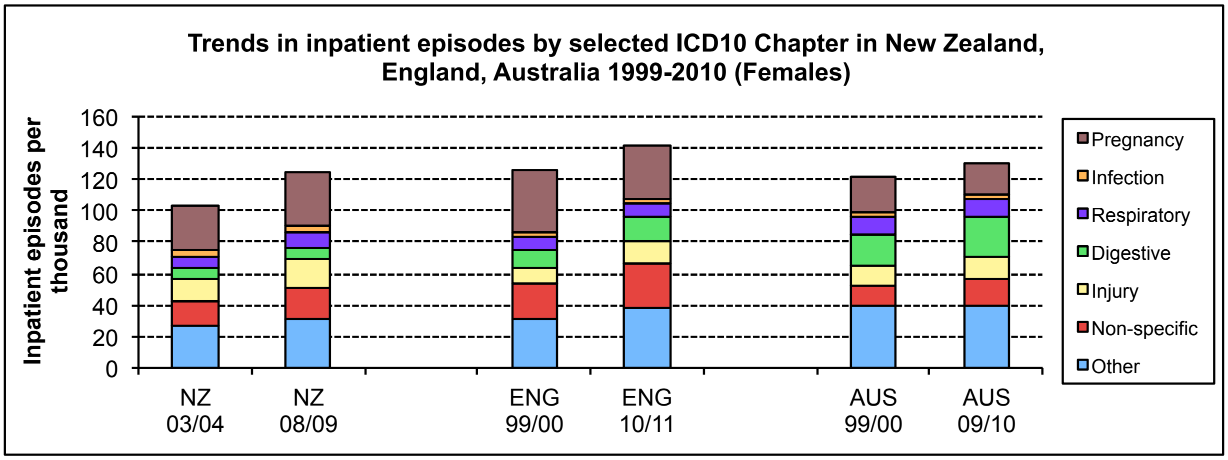
Note: Trends within Obstetrics/Gynaecology/Midwifery are influenced by an increase in the number of infants who are registered as being under the care of an obstetrician.

5.5 Comparison of English trends with Australian and New Zealand data

This section compares the trends in English data with those from Australia and New Zealand over a similar period. Figure 10 compares trends in adolescent inpatient activity by major ICD10 chapter for New Zealand, England and Australia. For both males and females, Australia in 2009/10 showed high levels of adolescent inpatient activity (M 110.2, F 130.5 episodes per thousand) but the slowest rate of increase (M +6.1%, F+ 6.9% over 10 years). Conversely, New Zealand in 2008/09 showed the lowest level of activity (M 90.0, F 124.7 per thousand) but the fastest rate of increase (Males +14.2%, Females +20.4% over 5 years). England saw a wide and stable gender disparity (Males 93.7, Females 141.8 per thousand) with activity for both sexes increasing by 13.0% over 11 years.

Figure 10: Trends in inpatient episodes by selected ICD10 Chapter in 3 countries.





Tables 11 and 12 present trends in inpatient activity for New Zealand, England and Australia by ICD10 chapter.

For males, there was a marked difference between countries in trends for inpatient activity related to injury or poisoning. New Zealand (32.1 per thousand) and Australia (30.1) were higher than England (20.6). Injury trends showed a rapid increase in New Zealand (19.3% increase in 5 years), a small increase in Australia (+3.9% over 10 years) and a small decrease in England (-1.7% over 11 years).

For females, activity related to pregnancy was high and increasing in New Zealand (34.3 separations per thousand, +20.4%), high and decreasing in England (34.4 FCEs per thousand, -13.3%), lower and decreasing in Australia (19.5 separations per thousand, -14.5%).

Notes

New Zealand data cover all publicly-funded hospital activity, English data all NHS activity and Australian data all activity in public and private hospitals.

Table 10: Inpatient episodes per thousand and percentage change by ICD10 Chapter in New Zealand, England, Australia between selected dates 1999-2010 (Males)

ICD10 Chapter	New Zealand 2003/4 to 2008/9		England 1999/00 to 2010/11		Australia 1999/00 to 09/10	
	Episodes 08/09	% change	Episodes 10/11	% change	Episodes 09/10	% change
I. Certain infectious and parasitic diseases	3.6	+15.2	1.9	+11.5	2.8	+3.8
II. Neoplasms	2.3	+10.1	4.9	+7.6	2.7	-4.5
III. Diseases of the Blood and Blood-Forming Organs and Certain Disorders involving the Immune Mechanism	1.1	-14.7	2.3	+18.7	1.8	+3.4
IV. Endocrine, Nutritional, and Metabolic Diseases	1.4	+15.5	3.0	+61.9	2.5	+60.2
V. Mental and Behavioural Disorders	2.8	-1.8	2.0	-40.4	5.6	-26.9
VI. Diseases of the Nervous System	2.2	+26.6	2.6	+51.8	2.7	+58.4
VII. Diseases of the Eye and Adnexa	0.7	+19.5	1.0	+13.3	0.7	-1.8
VIII. Diseases of the Ear and Mastoid Process	2.4	+12.0	1.5	-25.6	1.5	-6.9
IX. Diseases of the Circulatory System	1.7	+47.3	1.3	+32.8	1.5	+21.5
X. Diseases of the Respiratory System	7.5	+23.4	6.8	+6.4	8.9	+4.2
XI. Diseases of the Digestive System	8.1	+8.7	13.8	+39.8	19.2	+29.5
XII. Diseases of the Skin and Subcutaneous Tissue	4.5	+9.4	3.0	-11.4	5.0	+2.7
XIII. Diseases of the Musculoskeletal System and Connective Tissue	4.6	+12.3	5.3	+34.1	6.7	+5.8
XIV. Diseases of the Genitourinary System	3.0	+31.8	5.9	+38.1	3.6	+8.9
XVI. Certain Conditions Originating in the Perinatal Period	0.0	+94.6	0.0	-37.7	0.0	-37.2
XVII. Congenital Malformations, Deformations and Chromosomal Abnormalities	1.4	+0.4	2.7	+17.3	1.7	-14.0
XVIII. Symptoms, Signs and Abnormal Clinical and Laboratory Findings not elsewhere classified	6.1	+15.8	10.5	+28.0	5.3	+15.5
XIX. Injury, Poisoning and Certain Other Consequences of External Causes	32.1	+19.3	20.6	-1.7	30.1	+3.9
XXI. Factors Influencing Health Status and Contact with Health Services	4.4	-10.8	4.6	+0.2	7.8	-7.7
Total	90.0	+14.2	93.7	+13.0	110.2	+6.1

Table 11: Inpatient episodes per thousand and percentage change by ICD10 Chapter in New Zealand, England, Australia between selected dates 1999-2010 (Females)

ICD10 Chapter	**New Zealand 2003/4 to 2008/9**		**England 1999/00 to 2010/11**		**Australia 1999/00 to 09/10**	
	Episodes 08/09	% change	Episodes 10/11	% change	Episodes 09/10	% change
I. Certain infectious and parasitic diseases	4.1	+9.0	2.0	+12.8	3.5	+6.5
II. Neoplasms	2.6	+3.5	4.7	+5.5	3.3	-4.1
III. Diseases of the Blood and Blood-Forming Organs and Certain Disorders involving the Immune Mechanism	1.2	+11.0	2.0	+45.2	1.5	+10.3
IV. Endocrine, Nutritional, and Metabolic Diseases	2.3	+6.0	3.8	+68.0	2.9	+36.2
V. Mental and Behavioural Disorders	3.7	+30.1	2.5	-17.8	9.5	-5.5
VI. Diseases of the Nervous System	2.2	+21.0	2.8	+58.9	2.8	+51.9
VII. Diseases of the Eye and Adnexa	0.7	+48.5	1.4	+24.4	0.7	-4.8
VIII. Diseases of the Ear and Mastoid Process	1.8	-3.9	1.5	-22.3	1.4	-5.2
IX. Diseases of the Circulatory System	1.3	+23.5	1.2	+38.4	1.3	+28.0
X. Diseases of the Respiratory System	9.1	+19.4	8.9	+1.0	11.0	+3.7
XI. Diseases of the Digestive System	8.3	+9.8	16.3	+48.0	25.5	+27.8
XII. Diseases of the Skin and Subcutaneous Tissue	3.6	+21.7	3.1	-3.1	3.7	+4.5
XIII. Diseases of the Musculoskeletal System and Connective Tissue	4.1	(+18.4	6.4	+44.5	5.2	-0.9
XIV. Diseases of the Genitourinary System	6.9	+22.9	7.0	+31.1	5.9	-4.6
XV. Pregnancy, Childbirth, and the Puerperium	34.3	+20.4	34.4	-13.3	19.5	-14.5
XVI. Certain Conditions Originating in the Perinatal Period	0.0	-100.0	0.0	-45.3	0.0	+82.0
XVII. Congenital Malformations, Deformations and Chromosomal Abnormalities	1.1	-10.9	2.4	+28.5	1.6	-10.6
XVIII. Symptoms, Signs and Abnormal Clinical and Laboratory Findings not elsewhere classified	11.2	+21.8	18.0	+29.9	10.2	+34.2
XIX. Injury, Poisoning and Certain Other Consequences of External Causes	17.4	+25.2	14.0	+25.2	13.7	+8.4
XXI. Factors Influencing Health Status and Contact with Health	8.7	+48.0	9.4	+24.8	7.3	+18.3

Total	124.7	+20.4	141.8	+13.0	130.5	+6.9

5.6 Inequalities in inpatient and Emergency Department activity and health, England, 1999/2000 – 2009/10

This section relates to the methods described in section 2.6 and contains four different analyses of health inequalities in adolescence. The first is a cross-sectional analysis of ED and inpatient care in the most and least deprived deciles. Secondly, inequality data on healthcare activity in the most deprived decile are compared to activity in the general population. Thirdly, the Concentration Index (C) of inpatient activity is calculated for different age groups in order to assess the association between deprivation and inpatient use across the whole population. Concentration indices are then compared between age groups and over time. In order to interpret these findings more fully, the final section uses data from the Health Survey for England to analyse trends in the relative and absolute risk of poor health among children and young people over the last decade.

Figures 11 and 12 present ED and inpatient activity respectively. Age trends are shown for the most and least deprived deciles in each case.

There are wide differences in ED attendance between the most and least deprived deciles at all age, particularly in the early years and early adulthood. For inpatient activity, sex and deprivation are both important, with greater activity among boys in early childhood and among young women in adolescence. However, the sex divergence in adolescence is much greater in the most deprived decile, which may partly reflect higher rates of teenage pregnancy.

Figure 11: Age trends in Emergency Department attendance by sex and deprivation.

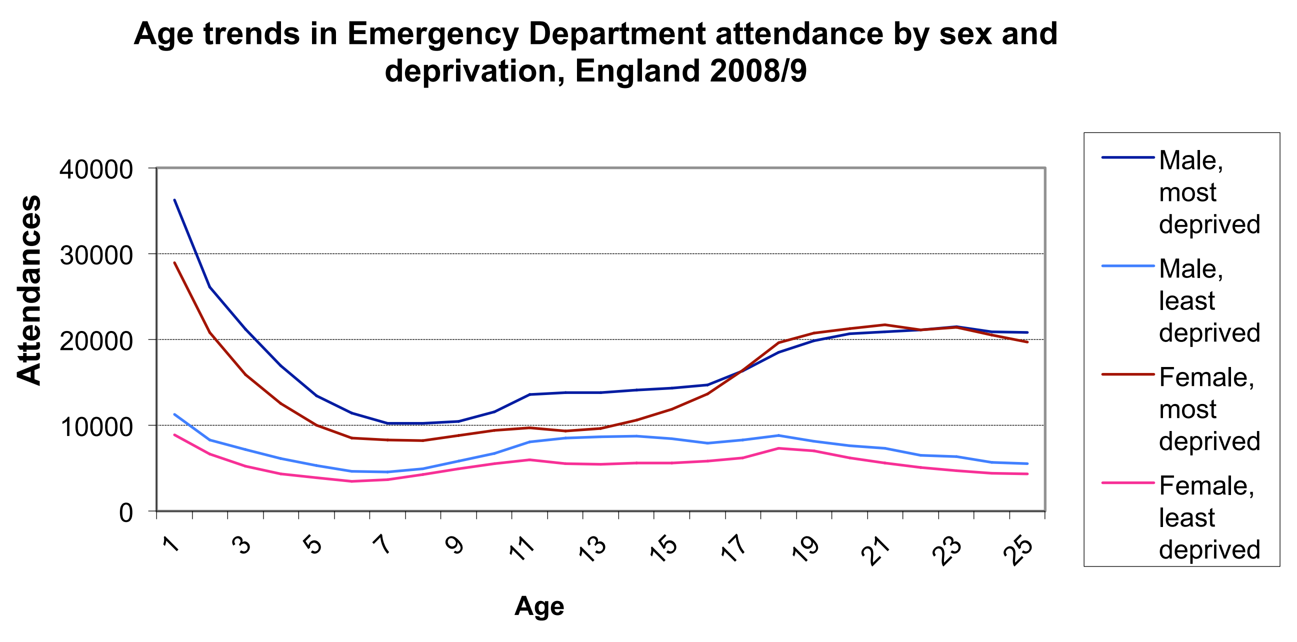


Figure 12: Age trends in inpatient episodes by sex and deprivation.

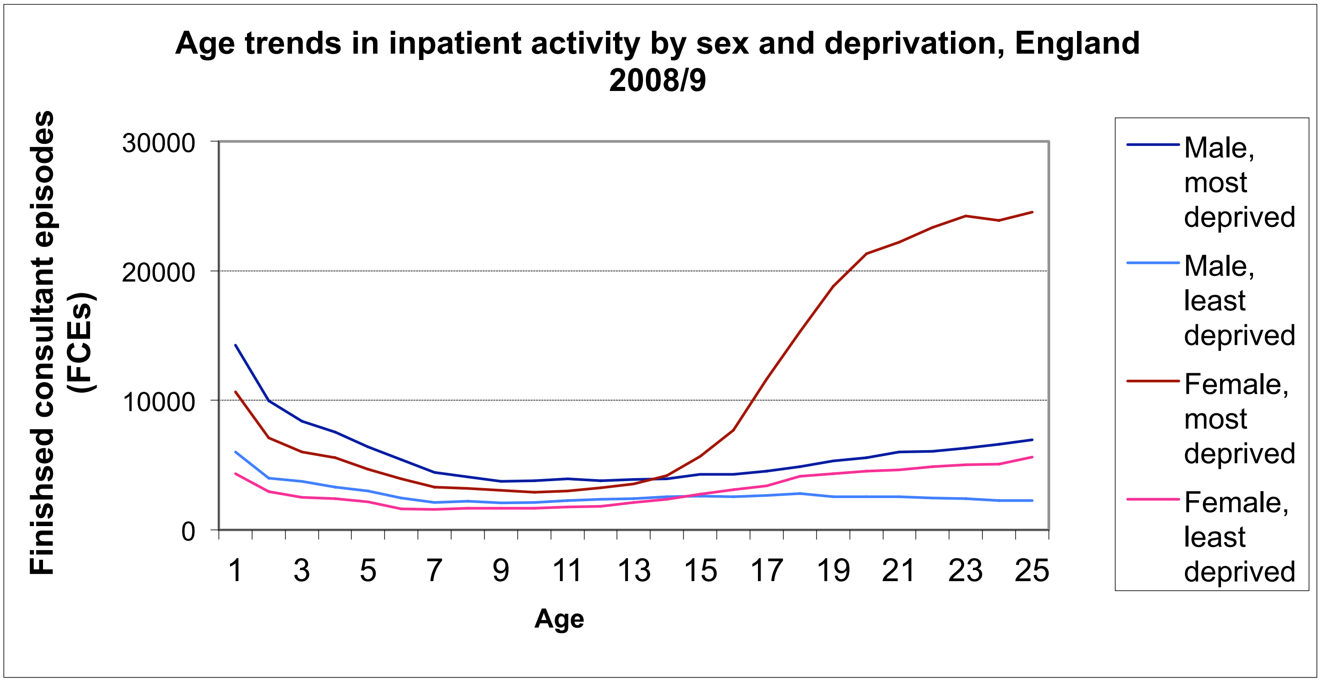


Figure 13 uses the ratios of activity in the most and least deprived deciles as an indicator of the social gradient i.e. the strength of the association between deprivation and increased healthcare activity at different ages. In the early years, this association is stronger for ED attendance than inpatient care, with minimal gender differences. The social gradient appears to become less significant during the primary school years, before increasing rapidly during adolescence, especially for females. By the early twenties, this ratio suggests that health inequalities in both settings are greater than at any earlier age. Health inequalities are analysed in more detail, using the more comprehensive Concentration Index, later in this section.

Figure 13: Age trends in the ratio of most deprived to least deprived patients, by s and hospital department.

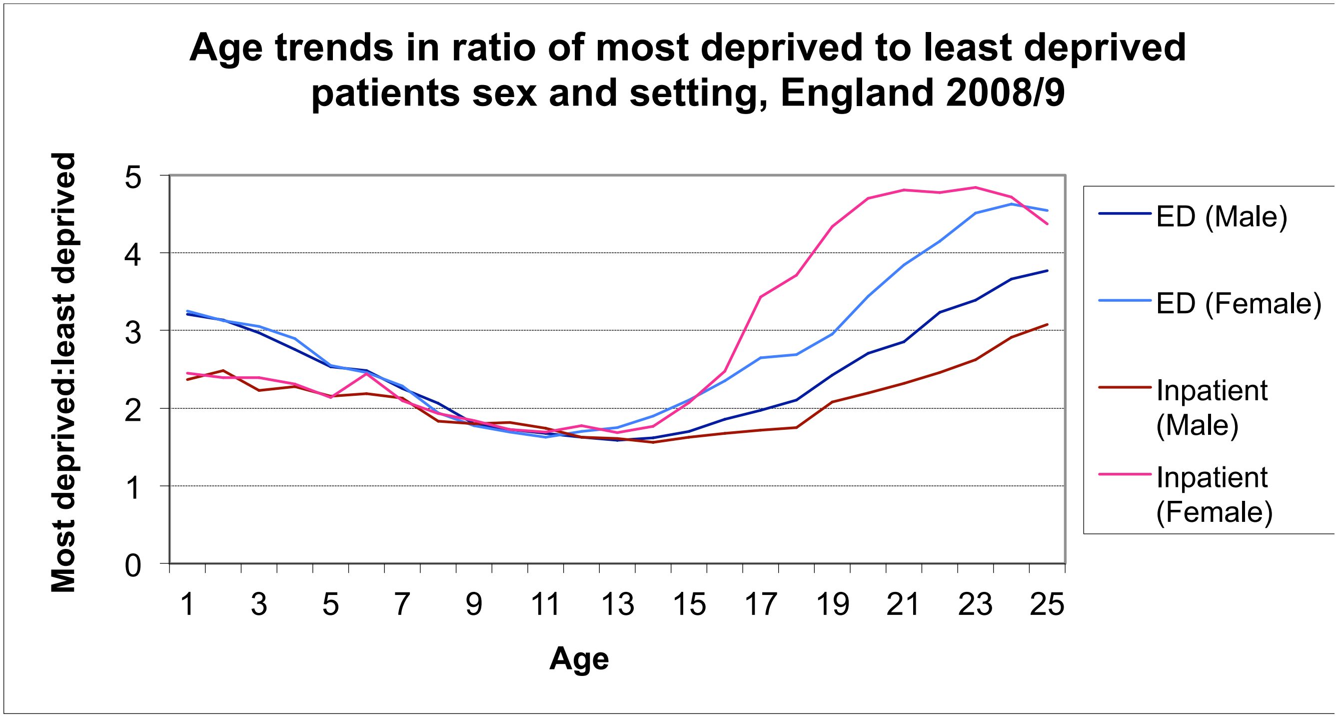
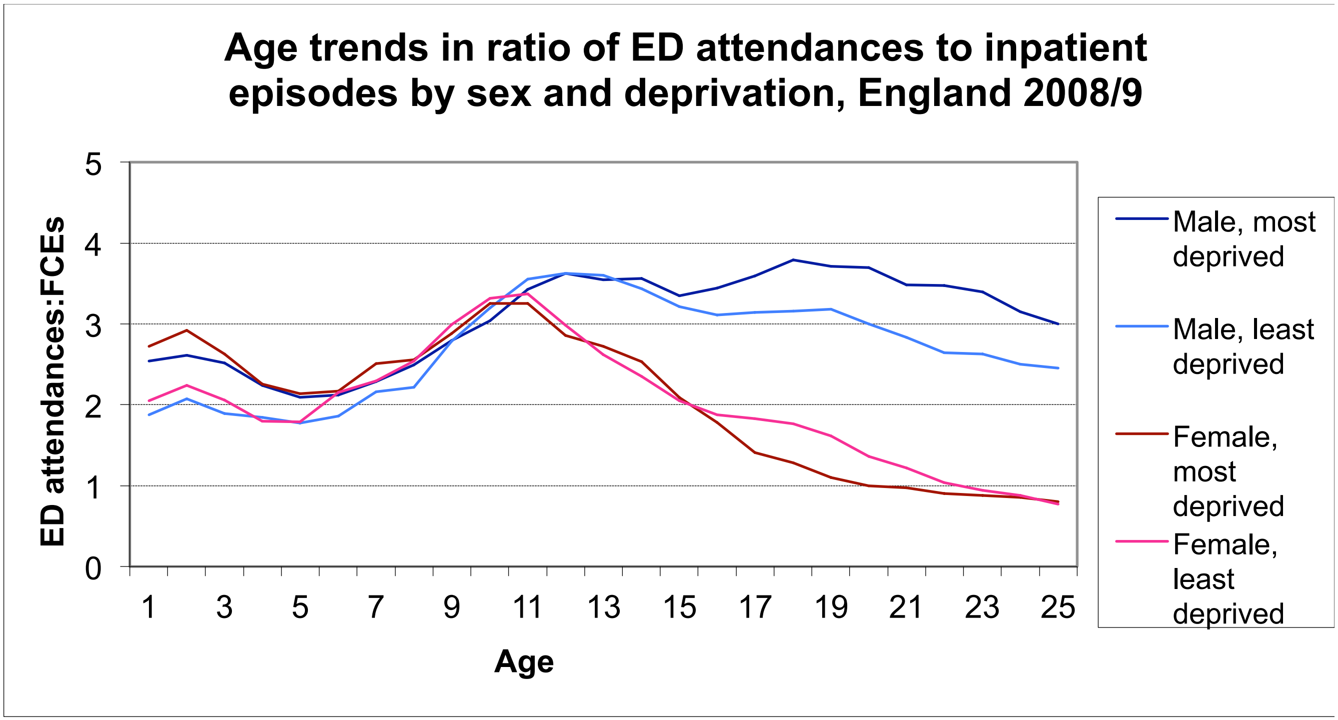


Figure 14 shows age trends in the ratio of ED attendances to inpatient episodes. As discussed in section 2.6, Sir Ian Kennedy and others have suggested that children and young people living in more deprived areas may rely disproportionately on emergency services. This is consistent with the different ratios of ED to inpatient care in children under 5. At age 1, the ratio of ED to inpatient care is higher in more deprived areas (Male 2.5 vs. 1.9, p<.001, Female 2.7 vs. 2.1, p<.001). This difference disappears by age 11, and differences thereafter largely reflect sex rather than IMD group.

Material from this section was presented at the Royal College of Paediatrics and Child Health Annual Conference in Glasgow, UK, 2012 (see Appendix E).

Figure 14: Age trends in the ratio of Emergency Department attendances to inpatient episodes.



Inequality trends in inpatient activity 1999/2000 and 2009/10

This section presents inequality trends in inpatient activity, separating by sex and age group. As described in section 2.6, two different sets of analyses are performed on the same data. Firstly, the most deprived decile is compared with the general population (Department of Health method). This is shown in Figure 15 and Table 13. Secondly, the concentration curves and concentration indices are used to the show the distribution across the whole population (World Bank method). These are shown in Figures 16 and 17 and Table 14.

The two sets of analyses produced very similar results for adolescents, although there were small differences for younger children. In the first analysis, inequality was low for infants; over time it was unchanged in relative terms and decreased in absolute terms. Inequality was slightly greater for 1-9s and increased in both relative and absolute terms. The reverse was seen for adolescents, especially older females, with higher levels of inequality which decreased in both relative and absolute terms.

The concentration indices show a slightly neater pattern of convergence throughout childhood and adolescence. Again, the lowest degree of inequality was seen in younger children but this increased significantly between 1999/2000 and 2009/10 in infants and females aged 1-4. The highest degree of inequality is seen in females aged 15-19 but this group also showed the greatest reduction over the ten year period. Other age groups showed a moderate degree of inequality, which reduced slightly over the ten year period.

Figure 15: Finished consultant episodes per thousand by age, sex and deprivation, England, 1999/2000 and 2009/10.

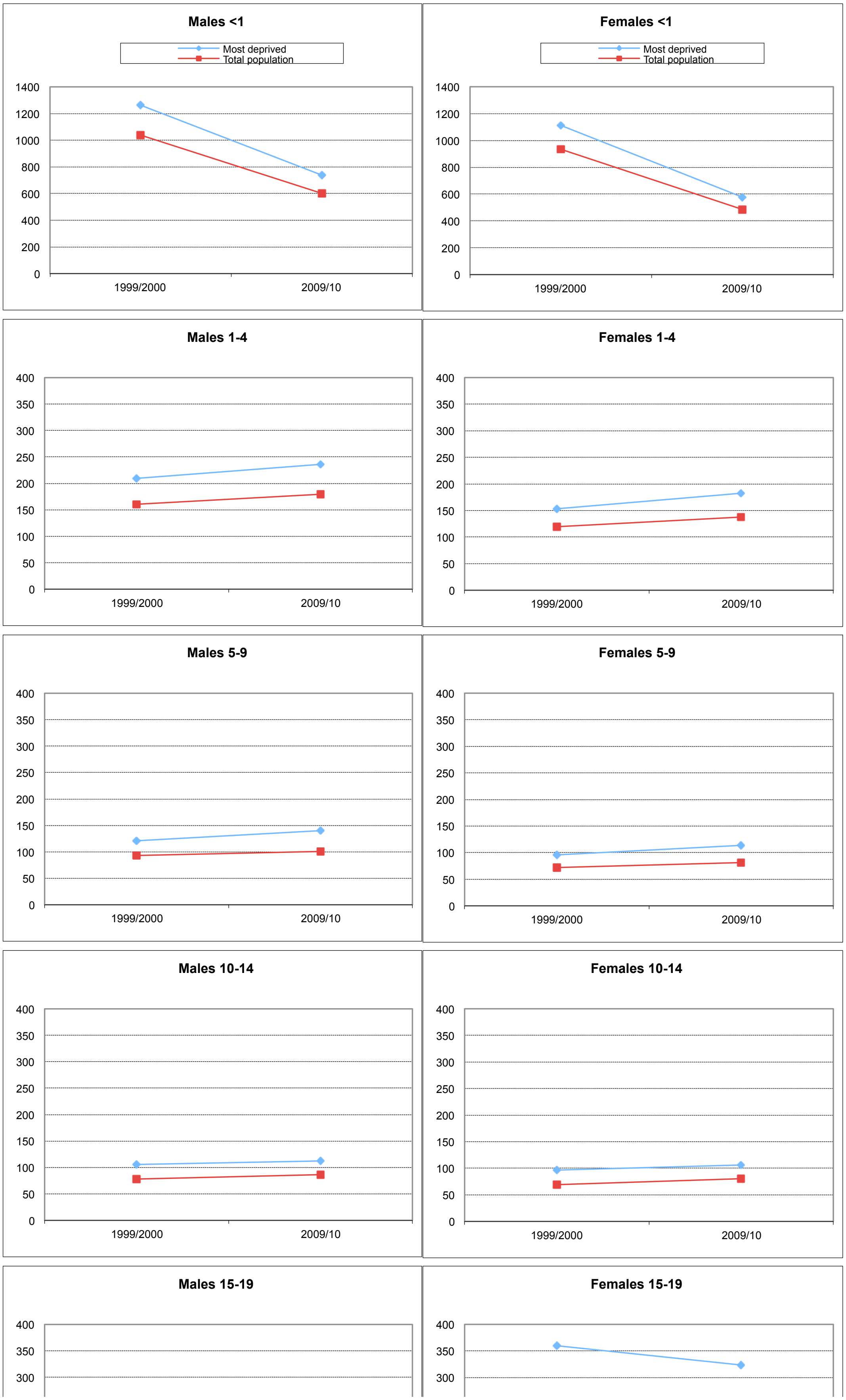
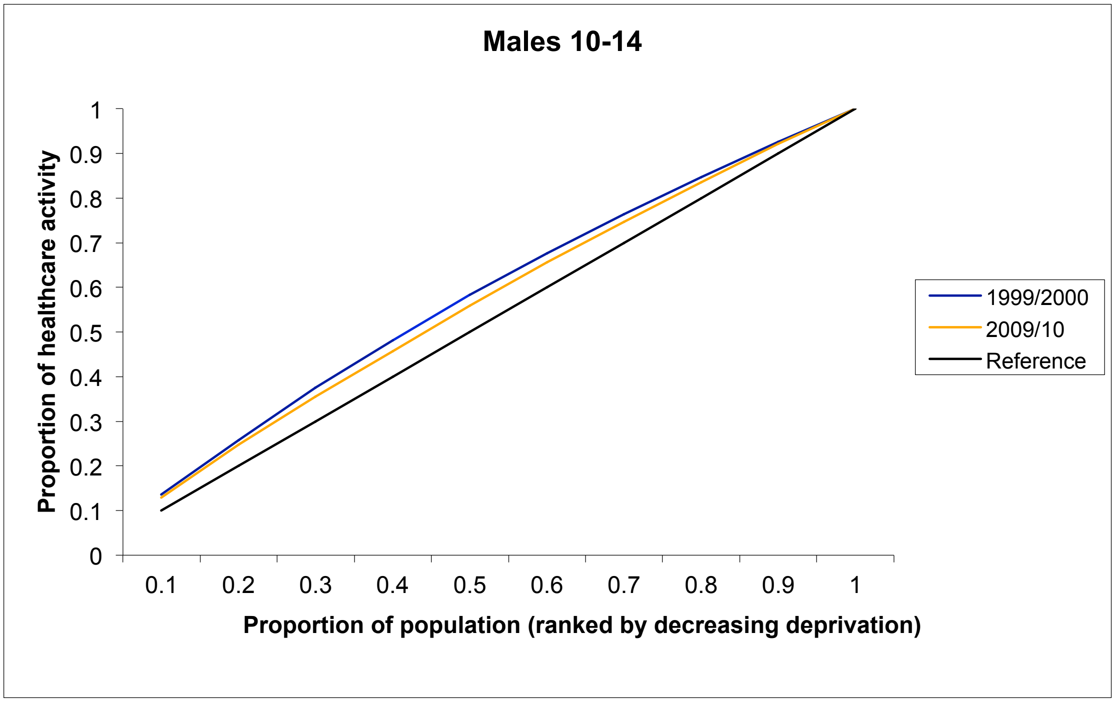


Table 12: Changes in relative and absolute inequality in inpatient activity by age and sex. England, 1999/2000 and 2009/10.

Age	Relative activity ratio + 95% CI (most deprived 10%:least deprived 90%)		Absolute difference in activity + 95% CI (most deprived 10% - least deprived 90%)	
	Male	Female	Male	Female
		1999/2000		
<1	1.22 (1.21,1.22)	1.19 (1.18, 1.19)	226.2 (220.8, 231.5)	175.3 (170.5, 180.1)
1-4	1.30 (1.30, 1.31)	1.28 (1.128, 1.29)	48.9 (48.1, 49.8)	33.9 (33.3, 34.6)
5-9	1.30 (1.30, 1.31)	1.33 (1.32, 1.34)	28.1 (27.5, 28.7)	23.8 (23.4, 24.3)
10-14	1.35 (1.35, 1.36)	1.39 (1.39, 1.40)	27.6 (27.0, 28.1)	27.2 (26.7, 27.6)
15-19	1.35 (1.34, 1.36)	2.06 (2.05, 2.07)	28.6 (28.1, 29.1)	185.4 (183.8, 187.1)
		2009/10		
<1	1.23 (1.22, 1.23)	1.19 (1.18, 1.19)	137.2 (134.1, 140.3)	91.4 (89.0, 93.9)
1-4	1.31 (1.31, 1.32)	1.33 (1.32, 1.33)	55.9 (54.9, 56.9)	44.9 (44.1, 45.7)
5-9	1.38 (1.38, 1.39)	1.40 (1.39, 1.40)	38.8 (38.1, 39.5)	32.3 (31.8, 32.9)
10-14	1.29 (1.28, 1.30)	1.32 (1.32, 1.33)	25.2 (24.6, 25.7)	25.9 (25.3, 26.4)
15-19	1.29 (1.28, 1.30)	1.68 (1.67, 1.69)	27.8 (27.3, 28.4)	130.8 (129.3, 132.3)
	Ratio of 2009/10 to 1999/2000 values		**Difference between 2009/10 and1999/2000 values**	
<1	1.01(1.00,1.02)	1.00 (1.00,1.01)	-89.0 (-97.4, -80.5)	-83.9 (-91.1,-76.6)
1-4	1.01(1.00, 1.01)	1.03 (1.03, 1.04)	7.0 (5.1, 8.9)	11.0 (9.6,12.4)
5-9	1.06(1.05,1.07)	1.05 (1.04, 1.06)	10.7 (9.5, 11.9)	8.5 (7.5,9.5)
10-14	0.95 (0.95,0.96)	0.95 (0.94, 0.96)	-2.4 (-3.4, -1.3)	-1.3 (-2.3, -0.3)
15-19	0.95(0.95,0.96)	0.81 (0.81, 0.82)	-0.8 (-1.9, 0.3)	-54.7 (-57.8, -51.5)

Figure 16: Concentration curves of inpatient activity by age and sex. England 1999/2000 and 2009/10.



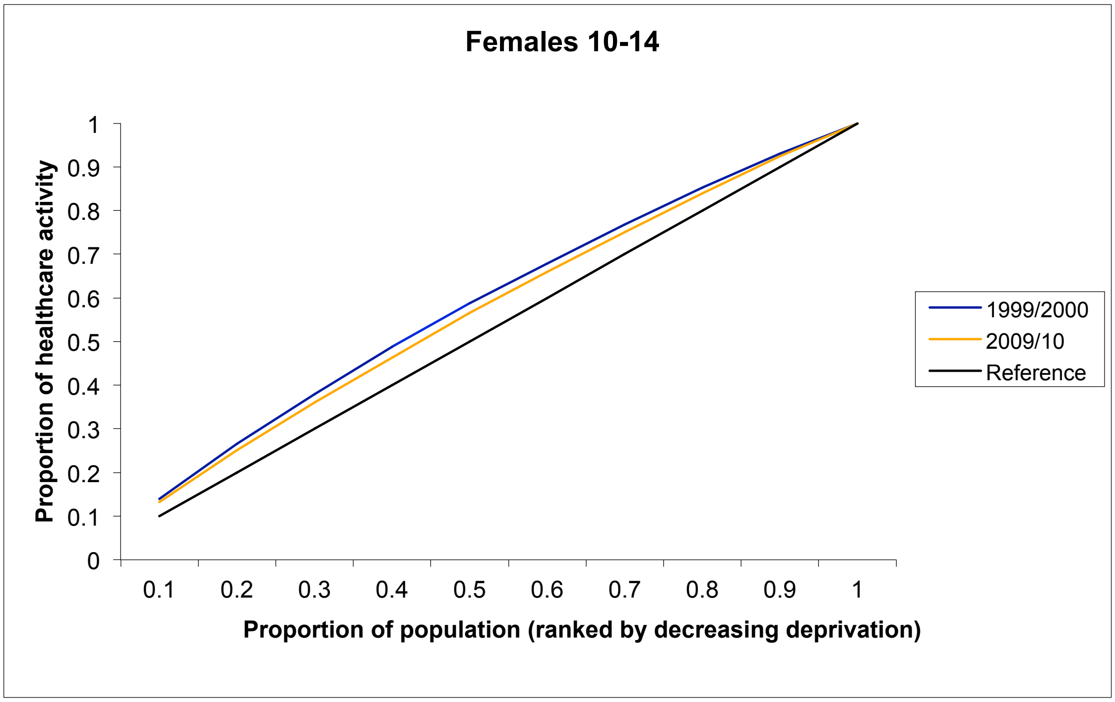
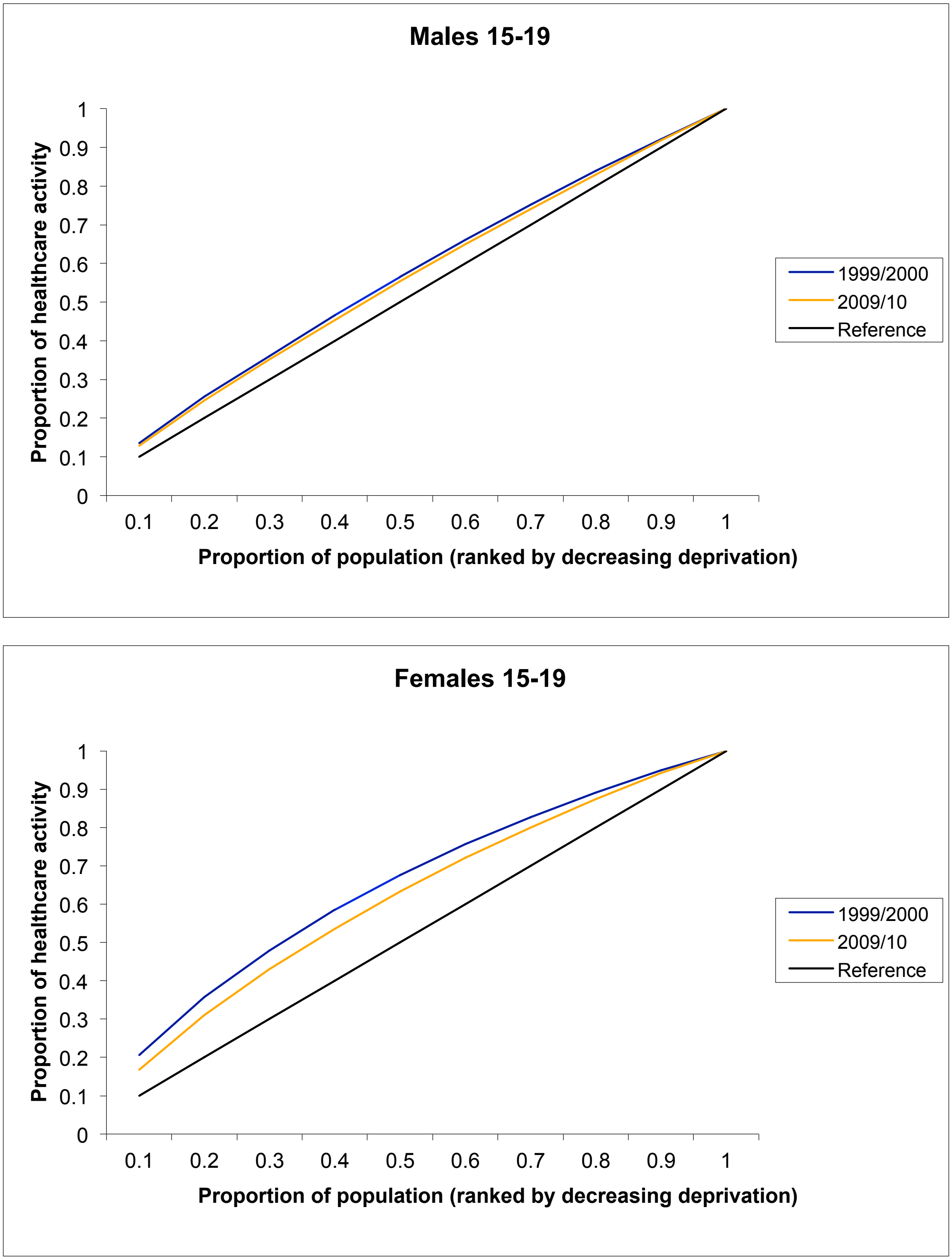


Figure 17: Concentration curves of inpatient activity by age and sex. England 1999/2000 and 2009/10.



The concentration indices in Table 14 represent the area between each concentration curve and the reference line (adjusted so that an index of 0 represents complete equality and an index of 1 complete inequality). Negative values signify greater healthcare use among more deprived groups.

Table 13: Concentration indices of inpatient activity by age and sex. England 1999/2000 and 2009/10.

Age	Sex	Concentration Index (Standard Error)	
		1999/2000	2009/10
<1	M	-0.046 (.002)	-0.071 (.002)
	F	-0.040 (.002)	-0.067 (.002)
1--4	M	-0.067 (.001)	-0.066 (.001)
	F	-0.064 (.001)	-0.070 (.001)
5--9	M	-0.104 (.001)	-0.093 (.001)
	F	-0.113 (.001)	-0.099 (.001)
10--14	M	-0.109 (.001)	-0.082 (.001)
	F	-0.118 (.001)	-0.090 (.001)
15--19	M	-0.091 (.001)	-0.075 (.001)
	F	-0.245 (.001)	-0.183 (.001)

As described in section 2.6, HES data were standardised to take account of the higher proportion of young children living in poorer areas. For reference, the total number of Finished Consultant Episodes and proportion of the age-specific population within each deprivation decile are presented in Tables 15 and 16 respectively.

Table 14: Total number of Finished Consultant Episodes by age, sex and deprivation decile. England, 1999/2000 and 2009/10.

	1999/2000					2009/2010				
Deprivation decile	0--1	1—4	5--9	10--14	15--19	0--1	1--4	5--9	10--14	15--19
Male										
Least	25677	15396	11706	10462	10372	14560	17603	12280	11704	13711
2	25494	15266	12141	10545	10562	15193	18341	12076	11924	14676
3	25573	15781	12430	10624	11022	15780	18331	12526	11879	14538
4	25656	16534	12915	11062	11214	16681	18948	12205	11929	14339
5	27518	17351	13854	11238	11482	17809	19579	12493	12265	14651
6	30052	18500	14339	12406	12152	19837	21546	14127	12995	15784
7	31230	20121	16115	12808	13025	22035	23785	14277	12783	16222
8	35990	22745	18089	14376	13789	24741	27277	15980	13850	17649
9	42467	28373	20504	15696	15584	27789	31629	19275	15866	19600
Most	51274	34876	24272	18785	18892	33344	40642	24640	18732	23141
Total	320931	204943	156365	128002	128094	207769	237681	149879	133927	164311
Female										
Least	22442	10574	8612	8243	13046	11013	12466	9098	9795	18226
2	21740	11069	8638	8613	15106	11926	12894	9305	10273	20818
3	22031	10948	8920	9039	15796	12539	13428	9371	10417	22031
4	22072	11929	9441	9313	17448	13058	13798	9286	10436	23308
5	23921	12229	9808	9324	19430	13214	14431	9722	10501	25690
6	25567	12962	10831	10097	22638	15008	15962	10613	11412	29355
7	26759	14616	12334	11042	27068	17099	17679	11032	11516	31849
8	30585	16446	13097	12055	32405	19429	19202	12677	12633	38825
9	36265	19397	15522	13588	40711	21550	23139	14724	14044	46150
Most	43329	24531	18423	16340	59187	25137	30307	19225	17018	57943
Total	274711	419412	115626	107654	262835	159973	173306	115053	118045	314195

Table 15: Percentage of population by sex, age, Index of Multiple Deprivation decile, England 2010.

Deprivation deciles	Male 0-4	Male 5--9	Male 10--14	Male 15--19	Female 0--4	Female 5--9	Female 10--14	Female 15--19
Least deprived	8.8	10.5	11.1	10.3	8.9	10.4	10.9	10.1
2	8.6	9.8	10.4	10.1	8.6	9.8	10.3	9.8
3	8.6	9.5	10.0	9.8	8.5	9.5	9.9	9.6
4	8.8	9.3	9.7	9.7	8.8	9.3	9.8	9.7
5	9.0	9.2	9.5	9.3	9.0	9.1	9.5	9.3
6	9.5	9.3	9.5	9.6	9.5	9.3	9.4	9.7
7	10.2	9.5	9.4	9.7	10.1	9.5	9.5	9.8
8	11.1	10.1	9.6	10.2	11.1	10.1	9.7	10.5
9	12.0	10.8	10.0	10.2	12.1	10.8	10.0	10.4
Most deprived	13.3	12.0	10.8	11.0	13.4	12.1	10.9	11.1
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Results of Health Survey for England analyses

This section presents trends in inequality using data from the Health Survey for England (HSE), 1999 and 2009. The proportion and relative risks of each health indicator by socioeconomic status and age group are presented for males (Table 17) and females (Table 18). Unless otherwise specified, findings described below refer to aggregated male and female data.

In 1999, 8.8% of children aged below 12 in the least deprived tertile were reported to be in poor general health, compared to 14.1% of the most deprived children. By 2009, the prevalence of poor general health had reduced for both groups, to 2.4% and 8.7% respectively. Thus, the absolute difference between social groups increased non-significantly from 5.2% (95% Confidence Intervals 1.8, 8.6) to 6.4% (3.9, 9.3) in 2009. The relative risk of poor general health related to greater deprivation increased from 1.6 (1.2, 2.2) in 1999 to 3.7(2.3, 5.9) in 2009 (p=.003).

The absolute difference in prevalence of a long-standing illness in young children increased from 1.2% (-3.0, 5.3) in 1999 to 7.2% (3.0, 11.6) p=.056, while the relative risk relating to deprivation increased from 1.1 (.9, 1.3) to 1.5 (1.2,1.8) (p=.04). The relative risk of obesity in females increased from 1.0 (.7, 1.5) to 1.9 (1.3, 2.6) (p=.02).

The relationship between deprivation and obesity increased non-significantly in young children, with the absolute difference changing from 4.5% (.2, 8.8) to 8.8% (4.3, 13.6) and the relative risk changing from 1.3 (1.0, 1.7) to 1.7 (1.3, 2.2).

Among the 13-16 age group, inequality in health indicators outcomes increased over this period for all outcomes but none reached statistical significance. A similar trend was seen for smoking in the 8-15 group, where the relative risk in males increased from 1.2 (.8, 2.0) to 2.4 (1.4, 4.1) p=.07.

Among young adults, the degree of inequality was stable for most outcomes, with no significant changes except for smoking. In 1999, young people from more deprived households were less likely to smoke than more affluent peers (14.6% vs. 21.5%), particularly among females. By 2009 this pattern had reversed, with young people from more deprived households more likely to smoke (25.5% vs. 16.4%). There was thus a change in absolute difference from -6.9% (-15.5, 1.4) to 9.1% (.3, 18.2) p=.01. The relative risk of smoking in more deprived groups increased from 0.7 (.4, 1.1) to 1.6 (1.0, 2.4) p=.01. No other changes were significant in this age group despite a strong trend to greater inequality in some indicators. For example, the relative risk of obesity in more deprived young men increased from 0.8 (.3, 2.8) to 3.4 (.7, 18.1) (p=.17).

An abstract containing material from this section has been accepted for presentation at the Social Science and Medicine Conference, London, September 2012 (see Appendix F).

Table 16: Proportion and relative risks of selected health indicators by age, sex and occupation of head of household, England 1999, 2009 (Males).

			1999			2009		
	Age	Deprivation	N	%	Relative Risk (95% CI)	N	%	Relative Risk (95% CI)
Poor general Health	2-12	Low	360	10.6	1	580	1.7	1
		Intermediate	581	11.2	1.06 (0.73,1.55)	463	2.8	1.63 (0.72, 3.68)
		High	350	15.1	1.43 (0.97,2.12)	248	10.1	5.85 (2.85, 11.99)
	13-16	Low	105	6.7	1	184	2.7	1
		Intermediate	191	9.4	1.41 (0.61,3.27)	163	8.0	2.93 (1.07, 8.06)
		High	125	12.8	1.92 (0.82, 4.49)	79	13.9	5.12 (1.84, 14.26)
	17-24	Low	101	11.9	1	110	13.6	1
		Intermediate	232	9.5	0.80 (0.41, 1.55)	146	17.8	1.31 (0.73, 2.34)
		High	133	6.0	0.51 (0.22, 1.19)	69	21.7	1.59 (0.83, 3.05)
High GHQ score	13-16	Low	88	5.7	1	145	5.5	1
		Intermediate	136	5.1	0.91 (0.30, 2.77)	133	4.5	0.82 (0.29, 2.30)
		High	93	3.2	0.57 (0.14, 2.31)	61	4.9	0.89 (0.24, 3.25)
	17-24	Low	88	8.0	1	99	7.1	1
		Intermediate	207	15.9	2.00 (0.92, 4.36)	138	10.9	1.54 (0.65, 3.63)
		High	112	16.1	2.02 (0.88, 4.62)	61	14.8	2.09 (0.82, 5.31)
Long-Standing Illness	2-12	Low	360	19.4	1	580	17.4	1
		Intermediate	581	20.8	1.07 (0.82, 1.39)	464	20.9	1.20 (0.93, 1.54)
		High	350	20.9	1.07 (0.80, 1.44)	248	29.4	1.69 (1.30, 2.20)
	13-16	Low	105	25.7	1	183	30.1	1
		Intermediate	192	25.0	0.97 (0.65, 1.46)	163	23.9	0.80 (0.56, 1.13)
		High	125	17.6	0.68 (0.42, 1.13)	79	24.1	0.80 (0.51, 1.25)
	17-24	Low	101	17.8	1	110	18.2	1
		Intermediate	233	18.9	1.06 (0.65, 1.74)	146	18.5	1.02 (0.60, 1.72)
		High	132	13.6	0.77 (0.42, 1.39)	69	23.2	1.28 (0.71, 2.29)
Obese	2-12	Low	301	11.3	1	485	13.0	1
		Intermediate	452	16.2	1.43 (0.98, 2.09)	389	15.2	1.17 (0.84, 1.62)
		High	283	19.8	1.75 (1.18, 2.60)	181	19.9	1.53 (1.06, 2.22)
	13-16	Low	75	21.2	1	170	17.1	1
		Intermediate	151	23.2	1.09 (0.66, 1.81)	152	24.3	1.43 (0.92, 2.20)
		High	99	16.2	0.76 (0.42, 1.40)	67	17.9	1.05 (0.57, 1.93)
	17-24	Low	89	5.6	1	99	2.0	1
		Intermediate	210	7.1	1.27 (0.48, 3.39)	139	7.9	3.92 (0.89, 17.29)
		High	108	4.6	0.82 (0.25, 2.76)	58	6.9	3.41 (0.65, 18.07)
Ever Smoked	8-15	Low	214	13.1	1	359	6.4	1
		Intermediate	341	14.7	1.12 (0.73, 1.72)	319	12.2	1.91 (1.17, 3.12)
		High	222	16.2	1.24 (0.78, 1.96)	158	15.2	2.37 (1.38, 4.07)
Current Smoker	16-24	Low	73	21.9	1	100	16.0	1
		Intermediate	162	29.6	1.35 (0.83, 2.21)	142	32.4	2.02 (1.22, 3.37)
		High	71	23.9	1.09 (0.60, 1.99)	65	24.6	1.54 (0.83, 2.86)

Table 17: Proportion and relative risks of selected health indicators by age, sex and occupation of head of household, England 1999, 2009. (Females)

			1999			2009		
	Age	Deprivation	N	%	Relative Risk (95%CI)	N	%	Relative Risk (95% CI)
Poor General Health	2-12	Low	318	6.9	1	559	3.0	1
		Intermediate	597	8.0	1.16 (0.71, 1.89)	447	4.7	1.54 (0.83, 2.89)
		High	319	12.9	1.86 (1.13, 3.05)	244	7.4	2.43 (1.27, 4.63)
	13-16	Low	100	8.0	1	179	6.1	1
		Intermediate	204	10.8	1.35 (0.62, 2.92)	153	9.2	1.49 (0.70, 3.18)
		High	123	17.1	2.13 (0.99, 4.61)	67	11.9	1.94 (0.82, 4.62)
	17-24	Low	113	12.4	1	94	11.7	1
		Intermediate	240	13.8	1.11 (0.62, 1.99)	110	19.1	1.63 (0.83, 3.21)
		High	160	23.1	1.87 (1.06, 3.29)	78	10.3	0.88 (0.37, 2.07)
High GHQ	13-16	Low	80	20.0	1	157	18.5	1
		Intermediate	169	11.2	0.56 (0.31, 1.03)	130	12.3	0.67 (0.38, 1.17)
		High	90	15.6	0.78 (0.41, 1.49)	50	22.0	1.19 (0.64, 2.21)
	17-24	Low	109	21.1	1	86	16.3	1
		Intermediate	206	18.0	0.85 (0.53, 1.36)	102	25.5	1.57 (0.87, 2.80)
		High	135	23.7	1.12 (0.70, 1.80)	72	22.2	1.37 (0.72, 2.60)
Long-Standing Illness	2-12	Low	318	16.7	1	560	14.5	1
		Intermediate	598	17.1	1.02 (0.76, 1.39)	447	15.2	1.05 (0.78, 1.42)
		High	318	17.6	1.06 (0.75, 1.49)	244	16.8	1.16 (0.82, 1.64)
	13-16	Low	100	26.0	1	179	19.6	1
		Intermediate	204	13.7	0.53 (0.33, 0.85)	153	23.5	1.20 (0.80, 1.82)
		High	123	15.4	0.59 (0.35, 1.01)	66	21.2	1.08 (0.62, 1.88)
	17-24	Low	113	15.0	1.00	94	24.5	1
		Intermediate	240	16.3	1.08 (0.64, 1.82)	110	29.1	1.19 (0.75, 1.88)
		High	160	13.8	0.91 (0.51, 1.64)	78	24.4	1.00 (0.59, 1.69)
Obese	2-12	Low	282	16.7	1.00	463	12.3	1
		Intermediate	495	14.1	0.85 (0.60, 1.19)	374	15.0	1.22 (0.86, 1.71)
		High	266	16.9	1.02 (0.70, 1.47)	197	22.8	1.86 (1.30, 2.64)
	13-16	Low	82	15.9	1.00	157	12.1	1
		Intermediate	169	18.9	1.19 (0.66, 2.15)	139	16.5	1.37 (0.78, 2.40)
		High	92	16.3	1.03 (0.52, 2.03)	56	17.9	1.48 (0.73, 2.98)
	17-24	Low	105	6.7	1.00	84	14.3	1
		Intermediate	198	7.6	1.14 (0.48, 2.70)	94	23.4	1.64 (0.86, 3.10)
		High	122	9.8	1.48 (0.60, 3.61)	68	20.6	1.44 (0.71, 2.91)
Ever Smoked	8-15	Low	216	8.3		355	10.1	1
		Intermediate	373	15.8	1.90 (1.15, 3.13)	316	8.9	0.87 (0.55, 1.40)
		High	214	12.1	1.46 (0.82, 2.58)	146	11.0	1.08 (0.62, 1.89)
Current Smoker	16-24	Low	71	21.1	1.00	89	16.9	1
		Intermediate	184	13.0	0.62 (0.34, 1.11)	109	31.2	1.85 (1.08, 3.17)
		High	114	8.8	0.42 (0.20, 0.87)	76	26.3	1.56 (0.86, 2.83)

Notes for Tables 17 and 18:

- Relative risks are calculated using the least deprived participants as the reference group.
- Data are weighted for sampling and other factors to be nationally representative
- Poor general health was defined as the proportion who assessed their health as ‘fair’, ‘bad’, or ‘very bad’.
- High General Health Questionnaire score was defined as a score of >=4.
- The third outcome used responses to the questions ‘Do you have a long-standing illness?’
- All three questions were addressed to young people themselves from the age of 13. Parents/carers were asked to respond on behalf of children up to the age of 12.
- Smoking was assessed using the question ‘Have you ever smoked?’ for respondents aged 8-15 and ‘Do you smoke nowadays?’ for those aged 16-24.
- Obesity was assessed using height and weight values measured at the time of the interview. Up to the age of 16, obesity was defined as a z score of weight for height higher than the 95% centile of the reference population. Above the age of 16, a Body Mass Index threshold of greater than 30 kg/m2 was used.

Chapter 6. Young people's experience of the NHS and comparison of care priorities between young and older adults.

6.1 Review of 38 national patient experience surveys 2001-2011
6.2 Analysis of children and young people's experience in 5 selected surveys
6.3 Healthcare experience and priorities of young versus older adults in the 2010 inpatient survey

Introduction

This chapter presents the results of analyses described in Chapter 3. Section 6.1 corresponds to the methods in section 3.1 and summarises the findings of Table 3. Sections 6.2 and 6.3 relate to sections 3.2 and 3.3 respectively. Material from this chapter has been published in two journal articles, which can be found in Appendices G and H.

6.1 Review of 38 national patient experience surveys 2001-2011

Details of the 38 surveys have previously been presented in Chapter 3 (Table 3). Under 16s are included in one survey out of 38, contributing approximately 55 000 out of more than 10 million subjects in major national surveys from 2001-2011 (less than 0.6%). 16-18 year olds were included in 35/38 surveys, and over 18s in 37/38. Data from young adults (16-24s) were presented separately to those from older adults (25+) in 6/37 surveys.

6.2 Analysis of children and young people's experience in 5 selected surveys

The experience of young patients compared to adults in 5 national surveys 2004-2009 is shown in Table 19.

In the Emergency Department Survey (2008), the experience of 16-24s was significantly poorer across all four measures of patient care than the experience of over 25s. There were no material differences in odds ratio or significance when further adjusted for the presence of a long term condition (data not shown).

In the Inpatient Survey (2009), females aged 16-24 were significantly less likely than older patients to report a positive experience on all four measures of care. Males aged 16-24 reported a significantly poorer experience than older males on most measures, but there was no difference in perceived involvement between patients aged 20-24 and those over 25. These findings remained unchanged after adjustment for the presence of a long term condition. Adjustment for the presence of a long term condition did increase the significance of differences for two questions in males; males aged 20-24 were significantly less likely to report good care than older adults (adjusted odds ratio 0.60, 95% CI .42 to .85, p=.004), and 16-19s were significantly less likely to report being involved in their care compared to older adults (adjusted OR 0.78, 95% CI .63 to .96, p=.02).

The GP Patient Survey (2009/10) data showed that the experience of care for 18-24s was significantly poorer than for older patients, across all 3 measures analysed.

In the 2004 Inpatient Surveys, children and young people were significantly less likely than adults to feel confidence and trust in their doctors or treated with respect and dignity. However, with the exception of males aged 0-11, young people were more likely than adults to be satisfied with their care overall. Perceived involvement in care was higher in 12-17s than adults, while there was no significant difference between 0-11s and adults.

Table 18: Experience of young patients compared to adults in selected surveys,, England, 2004-2009

		Male			Female		
		%	Unadjusted OR (95% CI)	p	%	Unadjusted OR (95% CI)	p
Emergency Department Survey (2008)							
Felt involved in care and treatment							
25+	(N = 40 453)	63.7	1.0		63.5	1.0	
20-24	(N = 2 697)	54.7	.69 (.61 to .78)	<.001	43.3	.44 (.40 to .49)	<.001
16-19	(N = 2 059)	56.4	.74 (.65 to .84)	<.001	47.9	.53 (.47 to .59)	<.001
Had confidence and trust in doctors/nurses							
25+	(43 527)	77.9	1.0		72.0	1.0	
20-24	(2 804)	62.8	.48 (.42 to .55)	<.001	53.6	.45 (.41 to .50)	<.001
16-19	(2 159)	71.5	.71 (.62 to .82)	<.001	57.8	.53 (.47 to .60)	<.001
Treated with respect and dignity							
25+	(43 655)	83.0	1.0		78.3	1.0	
20-24	(2 827)	68.5	.45 (.39 to .51)	<.001	54.7	.33 (.30 to .37)	<.001
16-19	(2 174)	70.8	.50 (.43 to .57)	<.001	60.3	.42 (.37 to .47)	<.001
Overall care good							
25+	(43 657)	90.2	1.0		88.4	1.0	
20-24	(2 817)	82.8	.53 (.45 to .62)	<.001	76.3	.42 (.38 to .48)	<.001
16-19	(2 160)	87.0	.73 (.60 to .88)	.001	80.3	.54 (.46 to .62)	<.001
Inpatient Survey (2009)							
Felt involved in care and treatment							
25+	(65 397)	53.7	1.0		52.1	1.0	
20-24	(1 238)	52.4	.95 (.79 to 1.15)	.58	45.1	.75 (.65 to .87)	<.001
16-19	(975)	48.8	.82 (.67 to 1.01)	.06	46.3	.79 (.67 to .93)	.005
Had confidence and trust in doctors							
25+	(66 049)	83.2	1.0		79.2	1.0	
20-24	(1 237)	76.9	.67 (.54 to .84)	.001	60.7	.41 (.35 to .47)	<.001
16-19	(984)	75.0	.61 (.48 to .77)	<.001	66.8	.53 (.45 to .63)	<.001
Treated with respect and dignity							
25+	(65 088)	83.9	1.0		77.1	1.0	
20-24	(1 233)	73.5	.53 (.43 to .66)	<.001	57.8	.41 (.35 to .47)	<.001
16-19	(971)	75.1	.58 (.46 to .73)	<.001	62.1	.49 (.41 to .57)	<.001
Overall care good							
25+	(64 950)	94.0	1.0		91.5	1.0	
20-24	(1 228)	91.6	.70 (.50 to .98)	.04	82.6	.44 (.37 to .53)	<.001
16-19	(967)	90.1	.58 (.41 to .81)	.001	85.5	.55 (.43 to .69)	<.001

Table 19 (continued)

		Male			Female		
		%	**Unadjusted OR (95% CI)**	**p**	**%**	**Unadjusted OR (95% CI)**	**p**
Young Patient and Adult Inpatient Surveys (2004)							
Patient felt involved in care and treatment							
16+	(85 745)	53.8	1.0		51.9	1.0	
12-17	(12 472)	60.6	1.32 (1.25 to 1.39)	<.001	60.5	1.42 (1.35 to 1.50)	<.001
0-11	(3 972)	52.8	.96 (.88 to 1.05)	.34	53.9	1.08 (.99 to 1.19)	.09
Had confidence and trust in doctors							
16+	(86 694)	83.0	1.0		78.6	1.0	
12-17	(16 447)	78.1	.73 (.69 to .77)	<.001	72.9	.73 (.69 to .77)	<.001
0-11	(42 322)	75.7	.64 (.61 to .66)	<.001	74.7	.80 (.77 to .83)	<.001
Treated with respect and dignity							
16+	(86 063)	83.0	1.0		76.4	1.0	
12-17	(16 481)	79.7	.78 (.73 to .82)	<.001	75.3	.92 (.87 to .97)	.004
0-11	(42 399)	78.7	.74 (.71 to .77)	<.001	78.0	1.10 (1.05 to 1.14)	<.001
Overall care good/excellent							
16+	(85 469)	93.7	1.0		91.2	1.0	
12-17	(16 450)	94.6	1.17 (1.06 to 1.30)	.001	93.4	1.35 (1.23 to 1.48)	<.001
0-11	(42 343)	93.5	.97 (.91 to 1.04)	.38	93.3	1.34 (1.25 to 1.43)	<.001

GP survey	**(2009/10)**		**All patients**	
		%	**OR (95% CI)**	**p**
Doctor good at involving you in decisions				
25+	(1 894 574)	72	1.0	
18-24	(101 124)	64	.69 (.68 to .70)	<.001
Had confidence and trust in doctor				
25+	(1 959 932)	95	1.0	
18-24	(101 846)	89	.40 (.39 to .41)	<.001
Satisfied with care received				
25+	(1 981 717)	90	1.0	
18-24	(102 551)	83	.52 (.51 to .53)	<.001

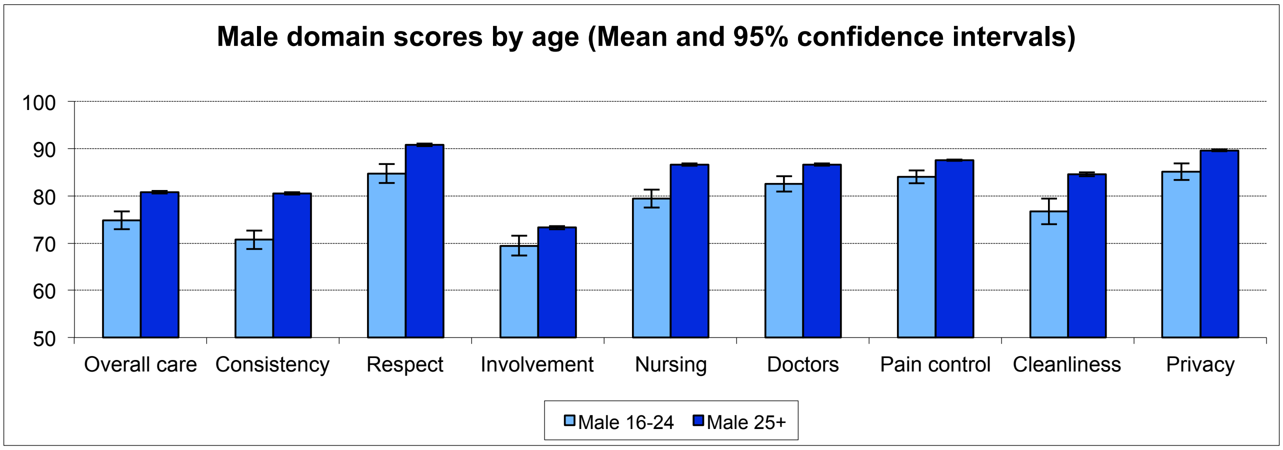
6.3 Healthcare experience and priorities of young versus older adults in the 2010 inpatient survey.

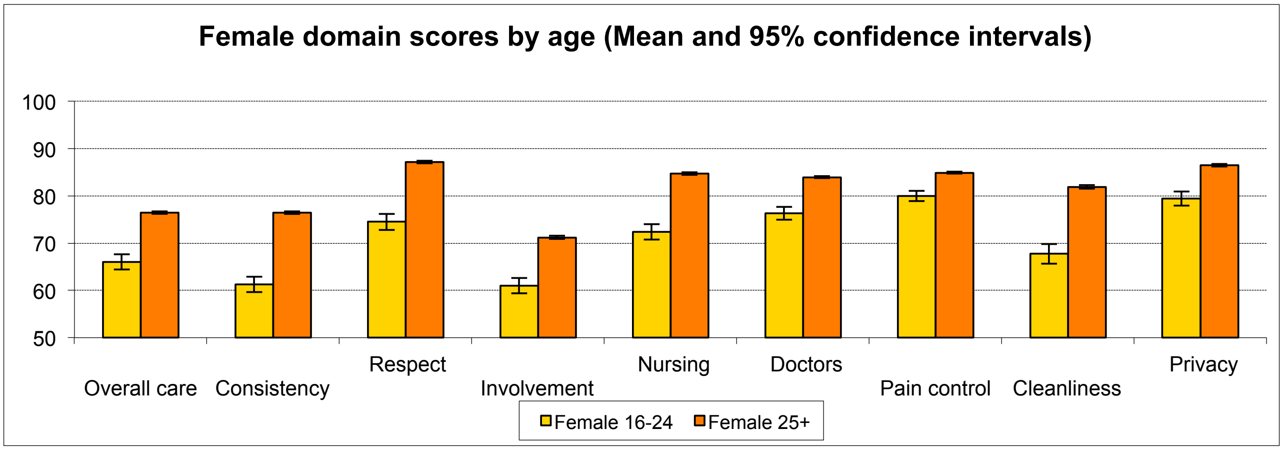
This section compares the patient experience of young versus older adults, using domains scores from 2010 Inpatient Survey, and then goes on to compare the inpatient priorities of the two groups.

The study included 66 006 patients aged 16 or over (2088 aged 16-24, 63918 aged 25+). Figure 18 presents overall care and domain scores by age and sex. The number of participants in each group and further details are presented in Table 20. Young adults reported a poorer experience than older adults in each domain of care, as did females compared to males (all p<.01).

Figure 19 presents the correlation coefficients between each domain and overall care rating. Full details are given in Table 21. Effectiveness of pain control was more strongly correlated with overall care rating in young males than older males (.585 vs. .527, p=.050). Compared to older women, young women's overall care ratings were more strongly correlated with scores for respect and dignity (.728 vs. .688, p=.004) and doctors' characteristics (.608 vs. .570, p=.039), while there was a trend for a weaker correlation with cleanliness (.504 vs. .539, p=.089). Young women's overall experience correlated more strongly with respect and dignity (.728 vs. .637, p <.001) than that of young men.

Figure 18: Inpatient domain scores by age and sex, Inpatient Survey, England, 2010.





Notes:

- Mean scores are presented for each domain, on a scale where 100 is the best possible score and 0 the worst possible.
- If available, age and sex data used information given by the patient. Otherwise, it was taken from information provided with the sample. See full survey report for further details.

Table 19: Overall rating of care and domain scores by age and sex, Inpatient Survey, 2009.

		Age 16-24			Age 25+		
		N	Mean	SE Mean	N	Mean	SE Mean
Overall care rating	Male	731	74.8	0.96	28525	80.7	0.14
	Female	1321	66.0	0.82	33399	76.5	0.14
	Total	2052	69.2	0.64	61924	78.4	0.10
Consistency	Male	742	70.7	1.00	29283	80.5	0.13
	Female	1340	61.2	0.82	34282	76.4	0.13
	Total	2082	64.6	0.64	63565	78.3	0.09
Respect	Male	729	84.7	1.01	28548	90.8	0.13
	Female	1323	74.5	0.88	33446	87.1	0.14
	Total	2052	78.1	0.68	61994	88.8	0.10
Involvement	Male	733	69.5	1.06	29033	73.3	0.17
	Female	1338	61.0	0.82	33921	71.2	0.16
	Total	2071	64.0	0.66	62954	72.1	0.12
Doctors	Male	739	79.4	0.99	29066	86.6	0.13
	Female	1334	72.3	0.83	33986	84.7	0.13
	Total	2073	74.9	0.64	63052	85.6	0.09
Nursing	Male	739	82.5	0.83	29070	86.6	0.12
	Female	1335	76.3	0.72	33990	83.9	0.12
	Total	2074	78.5	0.55	63060	85.2	0.09
Cleanliness	Male	727	84.0	0.70	28769	87.6	0.10
	Female	1325	80.0	0.55	33713	84.8	0.10
	Total	2052	81.4	0.44	62482	86.1	0.07
Pain control	Male	575	76.7	1.38	17918	84.5	0.21
	Female	1158	67.7	1.07	23103	81.9	0.20
	Total	1733	70.7	0.85	41021	83.1	0.14
Privacy	Male	733	85.1	0.88	29075	89.6	0.12
	Female	1337	79.4	0.76	33937	86.4	0.13

Total	2070	81.4	0.59	63012	87.9	0.09

Figure 19: Correlation between overall care rating and 8 domains of care.

Notes

Values represent the correlation coefficient between overall care rating and scores in each domain, together with 95% confidence intervals.

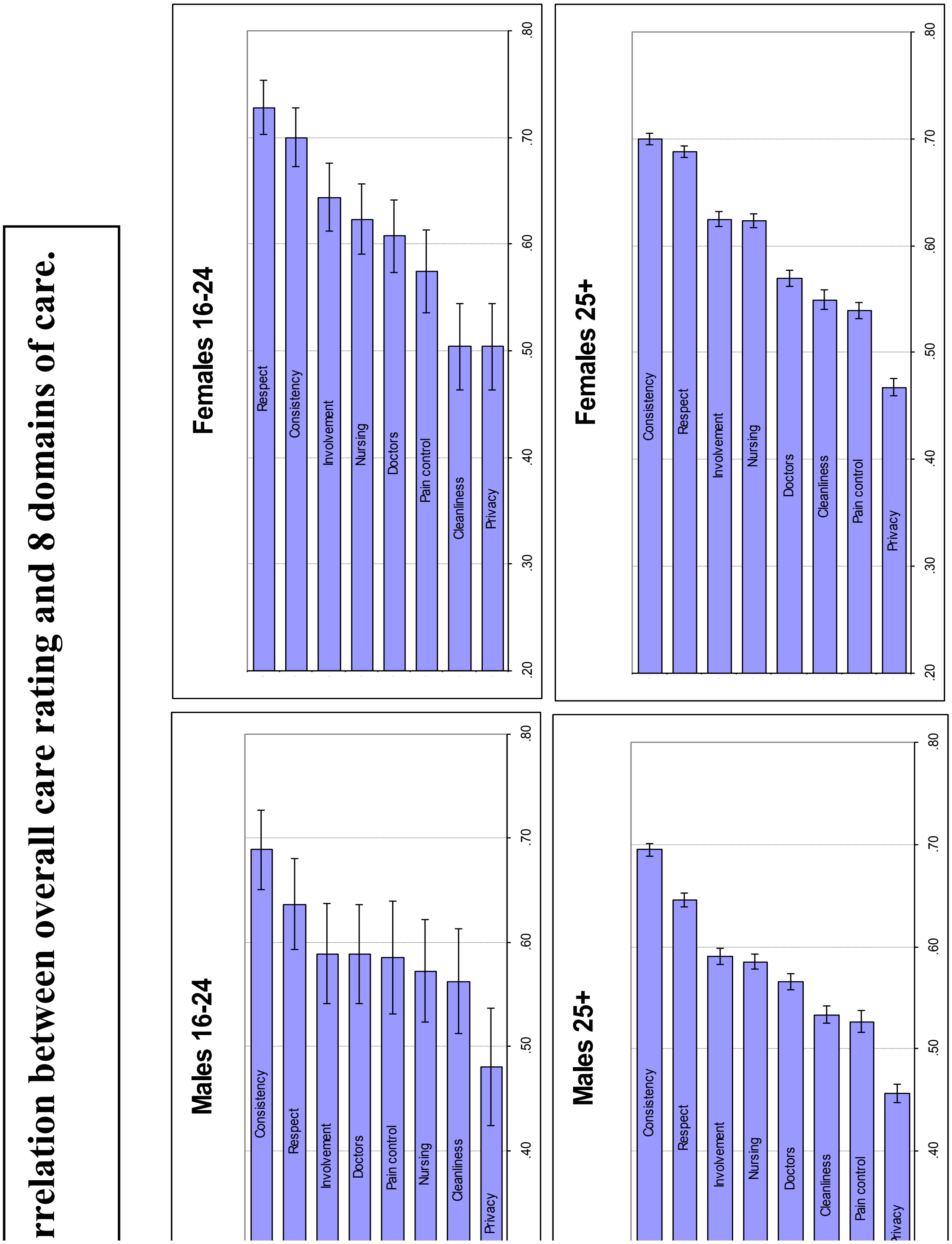


Table 20: Correlation coefficients between overall care rating and 8 domains of patient experience, by age and sex.

		16-24		25+	
		Male	**Female**	**Male**	**Female**
Consistency	Correlation	.689	.700	.695	.700
	Std. Error	.019	.014	.003	.003
	N	731	1320	28505	33352
Respect	Correlation	.637	.728	.646	.688
	Std. Error	.022	.013	.003	.003
	N	726	1313	28335	33111
Involvement	Correlation	.589	.644	.591	.625
	Std. Error	.024	.016	.004	.003
	N	723	1318	28250	32996
Doctors	Correlation	.589	.608	.566	.570
	Std. Error	.024	.017	.004	.004
	N	728	1312	28263	33034
Nursing	Correlation	.573	.623	.585	.623
	Std. Error	.025	.017	.004	.003
	N	728	1314	28285	33060
Cleanliness	Correlation	.563	.504	.533	.539
	Std. Error	.026	.021	.004	.004
	N	716	1304	27967	32752
Pain control	Correlation	.585	.574	.527	.549
	Std. Error	.028	.020	.005	.005
	N	565	1144	17479	22514
Privacy	Correlation	.480	.453	.456	.468
	Std. Error	.029	.022	.005	.004
	N	722	1317	28297	33009

Chapter 7. Validation of *You're Welcome* national quality criteria.

7.1 Validation of *You're Welcome* in inpatient settings
7.2 Validation of *You're Welcome* in the Emergency Department

Introduction

Results in this chapter relate to the methods described in Chapter 4. As previously discussed, the quantitative research planned in section 4.1 to 4.2 did not go ahead. No formal qualitative methodology was used to analyse the consultation findings from section 4.3, although several points are included in the discussion section. Sections 7.1 and 7.2 therefore correspond to the methods described in sections 4.4 and 4.5 respectively. (see Appendix I for the *YW* criteria, Appendix J for the related abstract presented at the RCPCH conference in Glasgow, and Appendix K for the article published in the Journal of Adolescent Health).

7.1 Validation of You're Welcome in inpatient settings

As described in Chapter 4.4, this section presents the results from a paper investigating the validity of the *You're Welcome* standards as a quality improvement tool in inpatient settings. Firstly, the survey questions are mapped to relevant *YW* criteria. Then, adjusted odds ratios are presented for overall patient satisfaction when specific aspects of the criteria were achieved.

Table 22 shows the 29 questions which best matched individual *YW* criteria. 11 questions were common to both inpatient and young people's surveys, 14 were included in the Young Peoples' Survey (YPS) only, and 4 were in the Inpatient Survey (IS) only

Table 21: Selected questionnaire items from the inpatient surveys mapped to *You're Welcome* major criteria.

Questionnaire item	Survey
Overall satisfaction	
'Overall, how would you rate the care you received?'	YPS & IS
***You're Welcome* criteria**	
1. Accessibility	
No questionnaire items identified.	
2. Publicity	
No questionnaire items identified.	
3. Confidentiality and consent	
No questionnaire items identified.	
4. Environment	
Did you feel that the hospital ward was a safe and secure place?	YPS
Did you feel threatened during your stay in hospital by other patients or visitors?	IS
In your opinion did the ward look nicely decorated?	YPS
Were you ever bored during your stay in hospital?	YPS
Did you feel friends or other relatives were welcome to visit you?	YPS
Were you given enough privacy when discussing your condition or treatment?	YPS & IS
Were you given enough privacy when you were being examined or treated?	YPS & IS
Do you think the hospital staff did everything they could to help control your pain?	YPS & IS
For most of your stay in hospital, what type of ward were you on?	YPS
When you were first admitted to a bed on a ward, did you share a sleeping area, for example a room or bay, with patients of the opposite sex?	IS
How would you rate the hospital food you were given?	YPS & IS
5. Staff training, skills, attitudes and values	

understand?	YPS & IS
Did doctors give your parent or guardian information about your care and treatment in a way that they could understand?	YPS
Did you have confidence and trust in the doctors treating you?	YPS & IS
In your opinion, did the doctor(s) who treated you know enough about your condition or treatment?	YPS
Did nurses give you the patient information about your care and treatment in a way that you could understand?	YPS & IS
Did nurses give your parent or guardian information about your care and treatment in a way that they could understand?	YPS
Did you have confidence and trust in the nurses treating you?	YPS & IS
In your opinion, did the nurses who treated you know enough about your condition or treatment?	YPS
Did you feel that you were treated with respect and dignity while you were in the hospital?	YPS & IS
Were you as involved as you wanted to be in decisions about your care and treatment?	YPS & IS
6. Joined-up working	
How would you rate how well the doctors and nurses worked together?	YPS & IS
How organized was the care you received in A&E or medical Admissions Unit?	YPS
Did hospital staff arrange the services you'd need after leaving hospital?	YPS
7. Young people's involvement in monitoring and evaluation of patient experience	
Were you asked your opinion about the quality of care?	IS
8. Health issues for young people	
If you had any worries or fears about your condition or treatment, did a doctor discuss them with you?	YPS
If you had any worries or fears about your condition or treatment, did a nurse discuss them with you?	YPS
While you were in hospital, did nurses give you emotional support and comfort when you needed it?	YPS
Did you find someone on the hospital staff to talk to about your worries and fears?	IS

Notes

- This table presents the 8 core criteria of the *YW* quality standards. For each criterion, there are multiple sub criteria which give detail on the expected level of service provision. 29 questionnaire items whose content matched one or more of these sub criteria are shown.
- YPS denotes this question was included in the Young Patient Survey, 2004. (25 questions)
- IS denotes this question was included in the Inpatient Survey, 2009 (15 questions)

Table 22: Descriptive data on survey respondents

Young Patient's Survey (ages 12-17)

Number of respondents

125 482 patients were contacted, of whom 62 276 (49.6%) returned a useable questionnaire.

16 706 were aged 12-17 (12-14: 8288; 15-17: 8418), of which the questionnaire was completed by the young person themselves in 7671 cases.

Gender

Males	3311	(43.2%)
Females	4346	(56.7%)
Not recorded	14	(0.2%)

Admissions within last 6 months

1	5373	70.0%
2-3	1600	20.9%
4 or more	466	6.1%
Total valid responses	7439	97.0%
Not recorded	232	3.0%

The numbers of valid responses for each questionnaire item are given below

Did you feel that you were treated with respect and dignity while you were in the hospital?	7637
Overall, how would you rate the care you received?	7618
Did you have confidence and trust in the doctors treating you?	7617
How would you rate how well the doctors and nurses worked together?	7616
If you had any worries or fears about your condition or treatment, did a doctor discuss them with you?	7615
Did doctors give you the patient information about your care and treatment in a way that you could understand?	7613
In your opinion, how clean was the hospital room or ward that you were in?	7610
Did nurses give you the patient information about your care and treatment in a way that you could understand?	7608

Did you have confidence and trust in the nurses treating you?	7608
In your opinion, did the doctor(s) who treated you know enough about your condition or treatment?	7605
If you had any worries or fears about your condition or treatment, did a nurse discuss them with you?	7603
Were you given enough privacy when discussing your condition or treatment?	7603
While you were in hospital, did nurses give you emotional support and comfort when you needed it?	7598
Did nurses give your parent or guardian information about your care and treatment in a way that they could understand?	7597
In your opinion, did the nurses who treated you know enough about your condition or treatment?	7597
Were you the patient involved as much as you wanted to be in decisions about your	7596
Were you given enough privacy when you were being examined or treated?	7594
In your opinion did the ward look nicely decorated?	7594
Did hospital staff arrange the services you would need after leaving hospital?	7590
In your opinion, were there enough nurses on duty to care for you in hospital?	7584
care and treatment?	
Did doctors give your parent or guardian information about your care and treatment in a way that they could understand?	7583
Were you ever bored during your stay in hospital?	7569
Did you feel that the hospital ward was a safe and secure place?	7594
How would you rate the hospital food you were given?	7561
For most of your stay in hospital, what type of ward were you on?	7534
Do you think the hospital staff did everything they could to help control your pain?	5426
Did you feel friends or other relatives were welcome to visit you?	5035
How organized was the care you received in A&E or medical Admissions Unit?	2707

Inpatient Survey (16-19)

Number of respondents

3472 young people aged 16-19 were invited to take part, of whom 988 (28.5%) returned useable questionnaires.

Gender

391 males (39.6%)

597 females (60.4%).

Presence of a long-standing condition

912 responded to the question about long-standing condition, of whom 268 (29.4%) replied that they did have some form of long-standing condition.

The number of valid responses for each question is given below

Did you have confidence and trust in the doctors treating you?	984
In your opinion, how clean was the hospital room or ward that you were in?	978
Did you feel threatened during your stay in hospital by other patients or visitors?	978
When you were first admitted to a bed on a ward, did you share a sleeping area, for example a room or bay, with patients of the opposite sex?	973
Did you have confidence and trust in the nurses treating you?	977
Were you involved as much as you wanted to be in decisions about your care and treatment?	975
Were you given enough privacy when discussing your condition or treatment?	971
Were you given enough privacy when being examined or treated?	971
Overall, did you feel you were treated with respect and dignity while you were in the hospital?	971
How would you rate how well the doctors and nurses worked together?	968
Overall, how would you rate the care you received?	967
When you had important questions to ask a doctor, did you get answers that you could understand?	929
When you had important questions to ask a nurse, did you get answers that you could understand?	923
If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?	898
How would you rate the hospital food?	879
During your hospital stay, were you ever asked to give your views on the quality of your care?	859
Do you think the hospital staff did everything they could to help control your pain?	823
Did you find someone on the hospital staff to talk to about your worries and fears?	710

How many minutes after you used the call button did it usually take before you got the help you needed? 625

Results of the validation study

Table 24 presents the satisfaction rates for questions relating to the inpatient environment. *YW* considers the environment to include the overall atmosphere and approach to care as well as the physical environment.(4) The 11 questions concerned pain control and feeling safe; the decoration, food and entertainment facilities available; whether privacy was respected and the atmosphere was welcoming for visitors; the type of ward where they were treated; and whether they had to share a sleeping area with patients of the opposite sex.

In the YPS, rating of care on a dedicated adolescent ward was significantly higher than for young people treated on an adult ward but not significantly better than for those treated on a children's ward. For the remaining 10 items across both surveys, overall rating of care was significantly higher when the *YW* criteria were met.

Table 25 presents satisfaction rates for questionnaire items regarding provider characteristics. 8 questions relate to the communication skills of doctors and nurses, the confidence and trust they inspired, and whether they appeared to have sufficient knowledge. The final two questions ask whether young people felt sufficiently involved in their care and were treated with dignity and respect during their stay. All of these questions were significantly associated with overall care rating.

Table 26 shows satisfaction rates for questions on joined-up working, young people's involvement in monitoring and evaluating the service, and health issues for young people. Questions on joined-up working covered organization in the Emergency Department, continuity of care after discharge, and the young people's impression of how well professionals worked together. All were significantly associated with overall satisfaction.

Only one question related to young people's involvement in service improvement and this was only asked in the IS. There was no significant difference in overall satisfaction between those who were asked for feedback their care and those who were not.
Within *YW*, the criteria of health issues for young people is interpreted broadly, including transition to adult services, health promotion, and an emphasis on understanding young people's perspectives and respecting their emotional, spiritual, and

psychosocial needs. The four questionnaire items all relate to young people's emotional needs: in particular whether worries and fears were addressed and emotional support was available. They were all significantly associated with overall satisfaction.

Table 27 presents the 10 questions in each survey that most strongly correlated with overall satisfaction. In the YPS, the content of 9/10 questions matched the *You're Welcome* criteria. The exception was cleanliness which did not directly match any *YW* criteria, although it is perhaps related to *YW* Criteria 4.1 which ensures that 'Care is delivered in a safe, suitable and young people friendly environment'.

The ten questions in the Inpatient Survey which most strongly correlated with satisfaction were all included within the *You're Welcome* criteria.

Table 23: Proportion of young people who reported a good overall rating of care, by response to questions about the hospital environment.

Questionnaire item	**Young Patient Survey (ages 12-17)**			**Inpatient Survey (ages 16-19)**		
	Good care (%)	Adjusted OR with 95% CI	p	Good care (%)	Adjusted OR with 95% CI	p

Did you feel that the hospital ward was a safe and secure place?						
Yes, definitely	96.8	1				
Yes, to some extent	84.5	.19 (.15-.23)	<.001			
No	66.9	.06 (.04-.10)	<.001			
Did you feel threatened during your stay in hospital by other patients or visitors?						
No				88.2	1	
Yes				71.4	.34 (.17-.69)	.003
In your opinion did the ward look nicely decorated?						
Yes, definitely	98.0	1				
Yes, to some extent	93.3	.28 (.21-.37)	<.001			
No	82.1	.09 (.07-.13)	<.001			
Were you ever bored during your stay in hospital?						
Hardly ever or not at all	98.7	1				
Some of the time	96.1	.33 (.21-.53)	<.001			
Yes, most or all of the time	83.3	.07 (.04-.10)	<.001			
Did you feel friends or other relatives were welcome to visit you?						
Yes, definitely	95.3	1				
Yes, to some extent	84.0	.28 (.22-.35)	<.001			
No	74.8	.16 (.10-.25)	<.001			
Were you given enough privacy when discussing your condition or treatment?						
Yes, always	97.4	1		95.3	1	
Yes, sometimes	90.1	.26 (.20-.32)	<.001	78.4	.18 (.11-.29)	<.001
No	75.4	.09 (.07-.11)	<.001	55.8	.06 (.04-.12)	<.001
Were you given enough privacy when you were being examined or treated?						
Yes, always	96.6	1		92.9	1	
Yes, sometimes	87.1	.23 (.19-.29)	<.001	73.8	.21 (.13-.34)	<.001
No	74.9	.10 (.07-.14)	<.001	28.0	.03 (.01-.08)	<.001

Do you think the hospital staff did everything they could to help control your pain?						
Yes, definitely	98.5	1		96.9	1	
Yes, to some extent	87.4	.10 (.07-.14)	<.001	81.9	.16 (.08-.30)	<.001
No	60.8	.02 (.02-.03)	<.001	42.0	.03 (.01-.05)	<.001
For most of your stay in hospital, what type of ward were you on?						
Adolescent	95.0	1				
Children	94.1	.83 (.62-1.12)	.23			
Adult	90.2	.48 (.34-.70)	<.001			
On ward, shared sleeping area with patient of opposite sex?				87.1	1	
No				66.1	.37 (.18-.77)	.007
Yes						
How would you rate the hospital food you were given?						
Very good/good	97.7	1		97.0	1	
Fair/poor	90.0	.22 (.16-.29)	<.001	81.2	.13 (.07-.26)	<.001

Notes

- The first column shows the percentage of respondents in each group who rated their care as excellent, very good or good when asked the question 'Overall, how would you rate the care you received?' Responses were on a 5 point Likert scale; the remaining options were fair and poor.
- The next column shows the odds ratios and 95% confidence interval between groups, using the most positive group as the reference in each case.
- Odds ratios were adjusted for gender and previous use of health services (using the number of recent admissions (YPS) or the presence of a long term condition (IS)).

Table 24: Proportion of young people who reported a good overall rating of care, by response to questions about provider characteristics.

Questionnaire item	**Young Patient Survey (ages 12-17)**			**Inpatient Survey (ages 16-19)**		
	Good care (%)	Adjusted OR, with 95% CI	p	Good care (%)	Adjusted OR, with 95% CI	p

Did doctors give you the patient information about your care and treatment in a way that you could understand?						
Yes, definitely	98.2	1		95.9	1	
Yes, to some extent	89.9	.17 (.13-.22)	<.001	84.8	.24 (.14-.42)	<.001
No	63.3	.03 (.02-.04)	<.001	46.7	.04 (.02-.07)	<.001
Did doctors give your parent or guardian information about your care and treatment in a way that they could understand?						
Yes, definitely	97.2	1				
Yes, to some extent	85.6	.18 (.14-.22)	<.001			
No	69.3	.07 (.05-.09)	<.001			
Did you have confidence and trust in the doctors treating you?						
Yes, always	98.2	1		96.9	1	
Yes, sometimes	86.2	.12 (.09-.15)	<.001	72.4	.09 (.05-.15)	<.001
No	51.5	.02 (.01 - .03)	<.001	35.7	.02 (.01-.04)	<.001
In your opinion, did the doctor(s) who treated you know enough about your condition or treatment?						
All doctors knew enough	98.3	1				
Most/some/no doctors knew enough	88.3	.14 (.11-.18)	<.001			
Did nurses give you the patient information about your care and treatment in a way that you could understand?						
Yes, definitely	98.1	1		96.6	1	
Yes, to some extent	88.2	.15 (.11-.19)	<.001	80.1	.16 (.09-.28)	<.001
No	63.3	.03 (.02 - .05)	<.001	45.2	.03 (.02-.06)	<.001
Did nurses give your parent or guardian information about your care and treatment in a way that they could understand?						
Yes, definitely	97.6	1				
Yes, to some extent	84.9	.14 (.12-.18)	<.001			
No	72.2	.07 (.05 - .09)	<.001			

Did you have confidence and trust in the nurses treating you?	97.9	1		98.5	1	
Yes, always	83.5	.11 (.09-.14)	<.001	74.0	.04 (.02-.09)	<.001
Yes, sometimes	43.9	.02 (.01-.02)	<.001	28.3	.01 (.00-.02)	<.001
No						
In your opinion, did the nurses who treated you know enough about your condition or treatment?						
All nurses knew enough	98.4	1				
Most/some/no nurses knew enough	90.5	.17 (.13-23)	<.001			
Did you feel that you were treated with respect and dignity while you were in the hospital?						
Yes, always	99.0	1		99.1	1	
Yes, sometimes	85.4	.06 (.05-.09)	<.001	73.1	.03 (.01-.07)	<.001
No	33.8	.01 (.00-.01)	<.001	11.5	.00 (.00-.00)	<.001
Were you as involved as you wanted to be in decisions about your care and treatment?						
Yes, definitely	98.0	1		95.5	1	
Yes, to some extent	92.1	.24 (.19-.32)	<.001	88.0	.36 (.20-.65)	.001
No	72.6	.06 (.04-.07)	<.001	65.8	.10 (.05-.17)	<.001

Notes

- See notes for Table 24.

Table 25: Proportion of young people who reported a good overall rating of care, by response to questions about joined up working, young people's involvement, and health issues for young people.

Questionnaire items	**YPS (ages 12-17)**			**IS (ages 16-19)**		
	% satis fied	Adjusted OR, with 95% CI	p	% satis fied	Adjusted OR with 95% CI	p
Joined-up working						
How would you rate how well the doctors and nurses worked together?						
Excellent/very good/good	97.6	1		96.9	1	
Fair/poor	43.0	.02 (.01-.02)	<.001	24.2	.01 (.01-.02)	<.001
How organized was the care you received in A&E or medical Admissions Unit?						
Very organized	98.2	1				
Fairly organized	90.3	.17 (.10-.28)	<.001			
Not at all organized	64.8	.03 (.02-.06)	<.001			
Did hospital staff arrange the services you'd need after leaving hospital? (excluding those who did not need any services)						
Yes	94.2	1				
No	82.2	.31 (.22-.43)	<.001			
Young people's involvement in monitoring and evaluation of patient experience						
Were you asked your opinion about the quality of care?						
Yes				92.9	1	
No				85.4	.43(.18-1.01)	.052
Health issues for young people						
If you had any worries or fears about your condition or treatment, did a doctor discuss them with you?						
Yes, completely	98.2	1				
Yes, to some extent/no	84.5	.10 (.08-0.14)	<.001			

If you had any worries or fears about your condition or treatment, did a nurse discuss them with you?						
Yes, completely	98.1	1				
Yes, to some extent/no	84.2	.11 (.08-.14)	<.001			
While you were in hospital, did nurses give you emotional support and comfort when you needed it?						
Yes, definitely	97.8	1				
Yes, to some extent/no	84.7	.11 (.09-.15)	<.001			
Did you find someone on the hospital staff to talk to about your worries and fears?						
Yes, definitely				97.1	1	
Yes, to some extent/no				75.5	.10 (.05-.21)	<.001

Notes

- The first column shows the percentage of respondents in each group who rated their care as excellent, very good or good when asked the question ‘Overall, how would you rate the care you received?’ Responses were on a 5 point Likert scale; the remaining options were fair and poor.
- The next column shows the odds ratios and 95% confidence interval between groups, using the most positive group as the reference in each case.
- Odds ratios were adjusted for gender and previous use of health services (using the number of recent admissions (YPS) or the presence of a long term condition (IS)).

Table 26: Questionnaire items which most strongly correlated with overall rating of care in the Young Patient Survey and Inpatient Survey.

Young Patient Survey (ages 12-17)

10 strongest correlations with overall rating of care

	Correlation coefficient
How would you rate how well the doctors and nurses worked together?	.747**
Did you feel that you were treated with respect and dignity while you were in the hospital?	.549**
Do you think the hospital staff did everything they could to help control your pain?	.479**
In your opinion, did the nurses who treated you know enough about your condition or treatment?	.400**
Did you have confidence and trust in the nurses treating you?	.448**
Did you have confidence and trust in the doctors treating you?	.427**
How organized was the care you received in A&E or medical Admissions Unit?	-.420**
Did nurses give you the patient information about your care and treatment in a way that you could understand?	.396**
Did doctors give you the patient information about your care and treatment in a way that you could understand?	.396**
In your opinion, how clean was the hospital room or ward that you were in?	.396**

Inpatient Survey (ages 16-19)

10 strongest correlations with overall rating of care

	Correlation coefficient
How would you rate how well the doctors and nurses worked together?	.806**
Overall, did you feel you were treated with respect and dignity while you were in the hospital?	.646**
Did you have confidence and trust in the nurses treating you?	.596**
Did you find someone on the hospital staff to talk to about your worries and fears?	.540**
Did the doctors or nurses give your family or someone close to you all the information they needed to care for you?	.536**
Did you have confidence and trust in the doctors treating you?	.512**
When you had important questions to ask a nurse, did you get answers that you could understand?	.499**
Were you involved as much as you wanted to be in decisions about your care and treatment?	.493**
When you had important questions to ask a doctor, did you get answers that you could understand?	.484**

opportunity to do so?

Notes

- Correlation coefficients were calculated between overall care rating and every other questionnaire item. The ten items with the strongest correlation are presented in order.
- ** denotes that the correlations are all statistically significant (p<.01).
- In the YPS, the question about cleanliness is not explicitly included in *YW*. The other 9 items in the YPS and all 10 items in the IS map directly to *YW* criteria (see Table 1).

7.2 Validation of You're Welcome in the Emergency Department

This section follows a similar format to 7.1, presenting the results from a submitted paper validating the *You're Welcome* standards as a quality improvement tool in Emergency Department (ED) settings. Firstly, the survey questions are mapped to relevant *YW* criteria. Adjusted odds ratios are then presented for overall patient satisfaction when specific aspects of the criteria were achieved. As only 16 questions from this survey matched the *YW* criteria, this paper included full descriptive data on each one. The number of respondents varied very little between questionnaire items in this survey; the exact numbers are therefore not included.

Table 28 shows the 16 questionnaire items which best matched individual *YW* criteria. No questions were identified which matched Criterion 2 (Publicity) or Criterion 7 (Involvement of young people in monitoring and improving the service). The criteria relating to confidentiality overlap to some extent with the questions on privacy (see below). However, no specific question related to confidentiality or consent was identified. Descriptive data on the study participants and responses to individual questionnaire items are presented in Tables 29-31.

Table 32 presents the satisfaction rates for questions relating to accessibility and the ED environment. *YW* considers the environment to include the overall atmosphere and concerned waiting time before speaking to a doctor/nurse, waiting time to be examined, and convenience of car parking. The four environment questions related to feeling safe, attention to pain control, and privacy when speaking to the receptionist or being examined by a nurse or doctor.

Table 33 presents the satisfaction rates for questions relating to staff, joined-up working and health issues for young people. 6 questions related to the attitudes and values of staff, their communication skills and ability to involve the young person, and the confidence and trust they inspired. The final 3 questions concerned continuity of care after discharge, whether different staff members gave a consistent message, and whether staff provided emotional support where necessary. For those aged 16-19 and 20-24, positive responses to all 16 questionnaire items were significantly associated with overall rating of care (all p<.001).

Table 34 presents the 10 questions that most strongly correlated with overall satisfaction. For 16-19s, the content of 5/10 questions matched the *You're Welcome* criteria. A sixth question asked whether the main reason for attending had been addressed and can be considered another measure of overall satisfaction. The remaining four items all concerned further aspects of provider characteristics, including whether members of staff were attentive, spent sufficient time talking to the young person and gave appropriate advice on discharge. For the group aged 20-24, addressing the main reason for attending correlated most strongly with overall satisfaction. Of the remaining 9 questions, 7 matched *YW* criteria and all related to provider characteristics and pain control.

Table 27: Selected questionnaire items from the Emergency Department survey mapped to *You're Welcome* major criteria.

Overall satisfaction

Overall, how would you rate the care you received in the Emergency Department?

***You're Welcome* criteria**

1. Accessibility

Was it possible to find a convenient place to park in the hospital car park?

How long did you wait before you first spoke to a nurse or doctor?

From the time you first arrived at the Emergency Department, how long did you wait before being examined by a doctor or nurse?

2. Publicity

No questionnaire items identified.

3. Confidentiality and consent

No questionnaire items identified (but see privacy questions under Criteria 4).

4. Environment

Were you given enough privacy when discussing your condition with the receptionist?

Were you given enough privacy when being examined or treated?

Do you think the hospital staff did everything they could to help control your pain?

While you were in the Emergency Department, did you feel bothered or threatened by other patients?

5. Staff training, skills, attitudes and values

While you were in the Emergency Department, did a doctor or nurse explain your condition and treatment in a way you could understand?

Did the doctors and nurses listen to what you had to say?

Did you have confidence and trust in the doctors and nurses examining and treating you?

Did doctors or nurses talk in front of you as if you weren't there?

Were you involved as much as you wanted to be in decisions about your care and treatment?

Overall, did you feel you were treated with respect and dignity while you were in the Emergency Department?

6. Joined-up working

Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left the Emergency Department?

Sometimes in a hospital, a member of staff will say one thing and another will say something quite different. Did this happen to you in the Emergency Department?

7. Young people's involvement in monitoring and evaluation of patient experience

No questionnaire items identified.

8. Health issues for young people

If you had any anxieties or fears about your condition or treatment, did a doctor or nurse discuss them with you?

Notes

- This table presents the 8 core criteria of the *YW* quality standards. For each criterion, there are multiple sub criteria which give detail on the expected level of service provision. 16 questionnaire items whose content matched one or more of these sub criteria are shown.
- Sexual and mental health do not form part of the core criteria and are therefore not included.

Table 28: Questionnaire respondents by age, sex and presence of a long-standing illness. Emergency Department Survey, England, 2008/9.

	16-19		**20-24**	
	N	**%**	**N**	**%**
Sex				
M	968	44.2	1109	38.9
F	1221	55.8	1741	61.1
Total	2189	100	2850	100

Yes	387	18.9	640	23.8
No	1658	81.1	2045	76.2
Total	2045	100	2685	100

Table 29: Questionnaire responses related to access and environment. Emergency Department Survey, England, 2008/9.

	Age 16-19		Age 20-24	
	N	%	N	%
Was it possible to find a convenient place to park in the hospital car park?				
Yes	900	71.7	988	68.9
No	355	28.3	446	31.1
Total	1255	100.0	1434	100.0
How long did you wait before you first spoke to a nurse or doctor?				
0 -15 minutes	616	30.0	795	30.1
16-30 minutes	639	31.1	821	31.0
31-60 minutes	426	20.8	552	20.9
> 60 minutes	371	18.1	477	18.0
Total	2052	100.0	2645	100.0
From the time you first arrived at the Emergency Department, how long did you wait before being examined by a doctor or nurse?				
No wait	165	8.0	192	7.2
1 - 30 minutes	661	32.1	822	30.7
31 - 60 minutes	483	23.4	689	25.7
1-2 hours	394	19.1	498	18.6
2-4 hours	293	14.2	375	14.0
> 4 hours	64	3.1	103	3.8
Total	2060	100.0	2679	100.0
Were you given enough privacy when discussing your condition with the receptionist?				
Yes, definitely	537	29.8	632	27.0
Yes, to some extent	917	50.9	1233	52.8
No	347	19.3	472	20.2
Total	1801	100.0	2337	100.0
Were you given enough privacy when being examined or treated?				
Yes, definitely	1488	69.2	1938	69.5
Yes, to some extent	563	26.2	706	25.3
No	99	4.6	143	5.1
Total	2150	100.0	2787	100.0
Do you think the hospital staff did everything they could to help control your pain?				
Yes, definitely	669	45.6	831	43.3
Yes, to some extent	472	32.2	628	32.7
No	327	22.3	459	23.9
Total	1468	100.0	1918	100.0
While you were in the Emergency Department, did you feel bothered or threatened by other patients?				
No	1780	83.1	2338	83.6
Yes, to some extent	282	13.2	336	12.0
Yes, definitely	81	3.8	122	4.4
Total	2143	100.0	2796	100.0

Table 30: Questionnaire responses related to staff, joined-up working and health issues for young people. Emergency Department Survey, England, 2008/9.

	Age 16-19		Age 20-24	
	N	%	N	%
While you were in the Emergency Department, did a doctor or nurse explain your condition and treatment in a way you could understand?				
Yes, completely	1250	60.2	1484	55.2
Yes, to some extent	654	31.5	891	33.1
No	171	8.2	315	11.7
Total	2075	100.0	2690	100.0
Did the doctors and nurses listen to what you had to say?				
Yes, definitely	1414	66.5	1748	62.8
Yes, to some extent	593	27.9	820	29.5
No	118	5.6	214	7.7
Total	2125	100.0	2782	100.0
Did you have confidence and trust in the doctors and nurses examining and treating you?				
Yes, definitely	1365	64.0	1593	57.3
Yes, to some extent	625	29.3	902	32.4
No	143	6.7	285	10.3
Total	2133	100.0	2780	100.0
Did doctors or nurses talk in front of you as if you weren't there?				
No	1655	78.2	2116	76.2
Yes, to some extent	314	14.8	426	15.3
Yes, definitely	148	7.0	234	8.4
Total	2117	100.0	2776	100.0
Were you involved as much as you wanted to be in decisions about your care and treatment?				
Yes, definitely	1052	51.7	1273	47.6
Yes, to some extent	705	34.7	962	36.0
No	276	13.6	437	16.4
Total	2033	100.0	2672	100.0
Overall, did you feel you were treated with respect and dignity while you were in the Emergency Department?				
Yes, all of the time	1405	65.2	1690	60.1
Yes, sometimes	608	28.2	873	31.1
No	142	6.6	247	8.8
Total	2155	100.0	2810	100.0
Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left the Emergency Department?				
Yes	997	63.6	1190	59.8
No	571	36.4	801	40.2
Total	1568	100.0	1991	100.0
Sometimes in a hospital, a member of staff will say one thing and another will say something quite different. Did this happen to you in the Emergency Department?				
No	1524	71.3	2004	71.8
Yes, to some extent	386	18.1	444	15.9
Yes, definitely	227	10.6	342	12.3

If you had any anxieties or fears about your condition or treatment, did a doctor or nurse discuss them with you?				
Yes, completely	629	47.4	798	42.0
Yes, to some extent	424	31.9	669	35.2
No	275	20.7	435	22.9
Total	1328	100.0	1902	100.0

Table 31: Proportion of young adults who reported good overall care, by response to questionnaire items on access and environment. Emergency Department Survey, England, 2008/9.

	Age 16-19			Age 20-24		
	Good care (%)	Adjusted OR with 95%CI	p	Good care (%)	Adjusted OR with 95%CI	p
Was it possible to find a convenient place to park in the hospital car park?						
Yes	87.6	1.00		84.3	1.00	
No	74.7	.42 (.30-.58)	<.001	66.1	.37 (.28-.48)	<.001
How long did you wait before you first spoke to a nurse or doctor?						
0 -15 minutes	92.2	1		90.2	1	
16-30 minutes	85.1	.53 (.37-.78)	0.001	82.8	.49 (.36-.67)	<.001
31-60 minutes	78.4	.32 (.22-.47)	<.001	74.1	.30 (.22-.40)	<.001
> 60 minutes	68.5	.18 (.13-.27)	<.001	58.1	.14 (.10-.19)	<.001
From the time you first arrived at the Emergency Department, how long did you wait before being examined by a doctor or nurse?						
No wait	95.8	1.00		94.3	1.00	
1 - 30 minutes	89.9	.39 (.17-.87)	0.022	89.2	.36 (.17-.75)	0.007
31 - 60 minutes	83.6	.23 (.10-.52)	<.001	81.4	.19 (.09-.39)	<.001
1-2 hours	83.5	.22 (.10-.49)	<.001	74.5	.13 (.06-.28)	<.001
2-4 hours	69.6	.10 (.04-.22)	<.001	58.1	.06 (.03-.13)	<.001
> 4 hours	43.8	.03 (.01-.09)	<.001	46.6	.04 (.02-.08)	<.001
Were you given enough privacy when discussing your condition with the receptionist?						
Yes, definitely	94.0	1.00		89.9	1.00	
Yes, to some extent	83.4	.34 (.22-.51)	<.001	81.5	.55 (.40-.74)	<.001
No	65.7	.14 (.09-.21)	<.001	58.9	.18 (.13-.25)	<.001
Were you given enough privacy when being examined or treated?						
Yes, definitely	90.3	1.00		87.3	1.00	
Yes, to some extent	71.9	.30 (.23-.39)	<.001	64.9	.28 (.22-.34)	<.001
No	42.4	.09 (.06-.14)	<.001	35.7	.09 (.06-.13)	<.001
Do you think the hospital staff did everything they could to help control your pain?						
Yes, definitely	95.8	1.00		93.3	1.00	
Yes, to some extent	80.9	.19 (.12-.30)	<.001	80.9	.31 (.22-.44)	<.001

No	55.1	.06 (.04-.09)	<.001	41.8	.06 (.04-.08)	<.001
While you were in the Emergency Department, did you feel bothered or threatened by other patients?						
No	85.8	1.00		81.1	1.00	
Yes, to some extent	73.8	.50 (.37-.68)	<.001	69.9	.55 (.42-.72)	<.001
Yes, definitely	58.0	.24 (.15-.40)	<.001	61.5	.39 (.26-.58)	<.001

Table 32: Proportion of young adults who reported good overall care, by response to questionnaire items on staff, joined-up working and health issues for young people. Emergency Department Survey, England, 2008/9.

	Age 16-19			Age 20-24		
	Good care (%)	**AOR 95% CI**	**p**	**Good care (%)**	**AOR 95% CI**	**p**
While you were in the Emergency Department, did a doctor or nurse explain your condition and treatment in a way you could understand?						
Yes, completely	94.2	1.00		93.5	1.00	
Yes, to some extent	75.4	.21 (.16-.29)	<.001	71.0	.18 (.14-.23)	<.001
No	39.8	.05 (.03-.07)	<.001	32.4	.04 (.03-.05)	<.001
Did the doctors and nurses listen to what you had to say?						
Yes, definitely	94.2	1.00		92.5	1.00	
Yes, to some extent	68.0	.14 (.10-.18)	<.001	65.6	.16 (.13-.20)	<.001
No	31.4	.03 (.02-.05)	<.001	18.7	.02 (.01-.03)	<.001
Did you have confidence and trust in the doctors and nurses examining and treating you?						
Yes, definitely	95.5	1.00		94.2	1.00	
Yes, to some extent	69.8	.12 (.09-.16)	<.001	69.5	.15 (.12-.20)	<.001
No	28.0	.02 (.01-.03)	<.001	22.8	.02 (.01-.03)	<.001
Did doctors or nurses talk in front of you as if you weren't there?						
No	88.7	1.00		84.2	1.00	
Yes, to some extent	69.1	.32 (.24-.43)	<.001	63.4	.34 (.27-.43)	<.001
Yes, definitely	56.1	.17 (.12-.24)	<.001	59.0	.27 (.20-.36)	<.001
Were you involved as much as you wanted to be in decisions about your care and treatment?						
Yes, definitely	94.6	1.00		94.0	1.00	
Yes, to some extent	81.6	.28 (.20-.39)	<.001	76.1	.21 (.16-.28)	<.001
No	44.6	.05 (.04-.07)	<.001	41.7	.05 (.04-.07)	<.001
Overall, did you feel you were treated with respect and dignity while you were in the Emergency Department?						
Yes, all of the time	97.0	1.00		95.3	1.00	
Yes, sometimes	67.4	.07 (.05-.10)	<.001	65.2	.09 (.07-.12)	<.001
No	14.8	.01 (.00-.01)	<.001	13.8	.01 (.01-.01)	<.001
Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left the Emergency Department?						
Yes	91.8	1.00		88.6	1.00	
No	65.9	.19 (.15-.26)	<.001	60.4	.20 (.16-.25)	<.001
Sometimes in a hospital, a member of staff will say one thing and another will say something quite different. Did this happen to you in the Emergency Department?						
No	88.9	1.00		86.6	1.00	
Yes, to some extent	75.7	.43 (.32-.57)	<.001	68.0	.36 (.28-.46)	<.001
Yes, definitely	58.2	.19 (.14-.26)	<.001	47.7	.15 (.12-.20)	<.001
If you had any anxieties or fears about your condition or treatment, did a doctor or nurse discuss them with you						
Yes, completely	95.1	1.00		94.9	1.00	
Yes, to some extent	77.6	.18 (.12-.29)	<.001	77.3	.19 (.13-.28)	<.001
No	47.6	.05 (.03-.08)	<.001	39.5	.04 (.03-.06)	<.001

Table 33: Questionnaire items which most strongly correlate with overall care rating, Emergency Department Survey, England, 2008/9.

Ages 16-19

	Correlation coefficient
Overall, did you feel you were treated with respect and dignity while you were in the Emergency Department?	.617**
Was the main reason you went to the Emergency Department dealt with to your satisfaction?	.616**
Did you have confidence and trust in the doctors and nurses examining and treating you?	.542**
Do you think the hospital staff did everything they could to help control your pain?	.516**
Did a member of staff tell you about any danger signals regarding your illness or treatment to watch for after you went home?	.516**
If you had any anxieties or fears about your condition or treatment, did a doctor or nurse discuss them with you?	.512**
If you needed attention, were you able to get a member of staff to help you?	.505**
Did the doctors and nurses listen to what you had to say?	.492**
Did you have enough time to discuss your health or medical problem with the doctor or nurse?	.487**
Did a member of staff tell you when you could resume your usual activities, such as when to go back to work or drive a car?	.487**

Ages 20-24

	Correlation coefficient
Was the main reason you went to the Emergency Department dealt with to your satisfaction?	.684**
Overall, did you feel you were treated with respect and dignity while you were in the Emergency Department?	.654**
Did you have confidence and trust in the doctors and nurses examining and treating you?	.594**
If you had any anxieties or fears about your condition or treatment, did a doctor or nurse discuss them with you?	.575**
Do you think the hospital staff did everything they could to help control your pain?	.560**
Did the doctors and nurses listen to what you had to say?	.547**
If you needed attention, were you able to get a member of staff to help you?	.545**
Did you have enough time to discuss your health or medical problem with the doctor or nurse?	.532**
While you were in the Emergency Department, did a doctor or nurse explain your condition and treatment in a way you could understand?	.531**
Were you involved as much as you wanted to be in decisions about your care and treatment?	.525**

** denotes p<.01

DISCUSSION

Chapter 8. Discussion

8.1 Trends in adolescent health service activity in England, Australia and New Zealand
8.2 Health inequality trends among English children and young people
8.3 Young people's inclusion and reported experience in national surveys
8.4 Young people's priorities and wider patient experience
8.5 *You're Welcome* validation in inpatient and Emergency Department settings

Introduction

This chapter discusses the research findings from Chapters 5-7 in the context of the policy and research literature discussed in Chapter 1, alongside the strengths and limitations of the methodology used in each case. Each section is discussed in the order that their respective methods and results were presented.

As described in Chapter 1, the three chapters of methods and three chapters of results relate to different steps in published assessment/improvement frameworks for health services, as well as tackling complementary aspects of the WHO principles for adolescent friendly care. They are intended to present different perspectives on existing NHS services for adolescents and inform different approaches to improving these services. Future research priorities and policy implications of these findings are then brought together in Chapter 9.

8.1 Trends in adolescent health service activity in England, Australia and New Zealand

The data I present in Chapter 5 provide the first published, comprehensive overview of adolescent inpatient activity in England and trends over the past decade. They highlight the significant proportion of healthcare activity that is devoted to adolescents, challenging traditional assumptions that this is a healthy time of life with little need for healthcare. Trend data show that adolescent activity has increased faster than in younger children over the past decade, mainly due to demographic trends. This material meets the need for national data on which to plan services, showing the principal reasons for hospital admission and the wide range of specialities responsible for adolescent care.

Data from Australia and New Zealand allow international comparison of trends in disease patterns and overall activity by age.

Data presented here show that young people in England account for at least 10% of health service activity in all major settings, increasing to over 20% of ED care. As in younger children, males are more frequent users of all health services during the early years of puberty. For inpatient and outpatient care, this position is reversed from around the age of 14, with far greater activity among females by late adolescence. ED care shows a different pattern, with increasing predominance of male activity during the mid-teen years, before a return to approximate gender parity by the end of the second decade. The major disease patterns are dominated by a large increase in pregnancy-related care among females between early and late adolescence. However, it is notable that activity increases for females in the majority of other disease categories as well. Time trends demonstrate the high and increasing proportion of care for digestive disorders and injuries in both sexes, as well as the high but decreasing proportion of pregnancy-related care for females.

Overall adolescent inpatient activity in England remains higher than in New Zealand and lower than Australia. However, activity appears to be converging within the three countries, with Australia showing the slowest rate of increase and New Zealand the fastest. England differs from the other countries in showing a wider gender disparity and a lower number of hospital admissions due to injuries or poisoning.

These findings confirm the suggestions of previous authors that adolescent medicine deserves greater attention than it currently receives from those responsible for service provision and training of healthcare professionals. Disease classifications trends in England, Australia and New Zealand allow epidemiological comparisons at local and national level, while data on admitting speciality may be used to guide commissioners, service providers and those responsible for post-graduate medical education. However, the main value of these data may be in challenging out-dated perceptions that adolescence is a healthy time of life, when individuals are less likely to use hospital services than in younger childhood.

Over the last 40 years, most high/middle income countries have made an epidemiological transition such that mortality during adolescence is now higher in than other stages of childhood outside infancy.(18) The relevance of this finding for health services has not always been clear, perhaps due to perceptions that the major causes of deaths in this age group (e.g. accidents, suicides) are less related to hospital care and less amenable to medical intervention than causes in younger age groups. In contrast, these data show that inpatient activity trends have mirrored the epidemiological transition, albeit comparing adolescent to children aged 2-9 rather than aged 1-9. I found that the average number of inpatient episodes in England is higher during adolescence than among younger children aged 2-9. Compared to younger children, activity has increased almost twice as fast in this age group over the last decade.

Strengths and limitations

Strengths of this study are the use of robust, national level data, providing a firm evidence-base to guide improvement strategies, particularly for hospital care. Another strength is the ability to compare English findings with data from Australia and New Zealand, which also provide universal health coverage. The three countries differed in some respects but showed that English trends of adolescent activity were plausible, increasing faster than in Australia but more slowly than in New Zealand over the last decade.

One limitation of this analysis is the focus on inpatient care, which represents a small proportion of all contact between the health service and young people. High quality inpatient provision is a consistent priority of young people themselves,(87) as well as being emphasised by policy makers in recent English, US and WHO reports. Yet, inpatient services frequently receive little attention in the adolescent research literature, including the 2007 Lancet series and subsequent studies.

As discussed in section 2.1, a more comprehensive analysis would also have compared the number of bed days and the number of spells, in addition to Finished Consultant Episodes. However, these analyses were beyond the scope of the thesis and, particularly in the case of spells, were not so amenable to international comparisons, as the data are recorded and presented differently in the three countries.

The quality of HES data is known to be very variable, with previous authors finding that some codes are frequently unreliable. For example, Gilbert found that ED codes for suspected maltreatment were not always reliable, but the quality of inpatient coding was significantly better.(223)

Data quality issues are all the more apparent when comparing between countries. Despite using the same classification system and presenting data in very similar ways, there is considerable potential for more subtle biases to exist, which are not apparent when looking at the final data. For example, little information is available on the exact details by which data are collected, data coders are recruited and trained and data is aggregated from different sites, or how data are cleaned and missing data imputed or omitted. It is likely that there are differences in some or all of these factors between countries, which could influence the final results.

More obviously, the trend data are available for different years in each country. However, the similarity in many trends between countries supports the validity of the overall conclusions, even though caution should be used in interpreting the precise numbers.

Discussion/comparison with literature

The challenges involved in improving inpatient adolescent care are highlighted by the diversity of admitting specialities. Despite efforts by some of the adult-oriented medical Royal Colleges, national policy initiative for adolescent health have had much less impact in many specialities that are responsible for treating large numbers of adolescents, including Obstetrics/Gynaecology and a range of surgical specialities.

Although detailed analysis of primary care data is beyond the scope of this thesis, some of the same concerns apply to care of adolescents in General Practice. As discussed in Chapter 1, the adolescent health group of the Royal College of General Practitioners has been active in a range of initiatives to improve young people's care but standards of care continue to be very variable between practices.

Time and resource constraints also limited further analysis of inpatient data. For a fuller understanding of logistical and financial aspects of adolescent care, it would be useful to extend the analysis of Finished Consultant Episodes to other measures of inpatient activity, including the number of bed days and total number of hospital admissions. Similarly, it would be interesting to examine the interaction between inequality and disease or speciality-specific care, particularly in the light of the recently-published Atlas of Variation for children and young adults, which displays large variation in admission rates for asthma, epilepsy, diabetes, etc between local areas, partly attributed to deprivation of the local population.(224)

Scoping review

The review revealed a disparity in hospitalisation trends between countries, depending on the health system. Australia, New Zealand, and England, which provide universal health services, saw increasing inpatient activity in recent years for both children and young adults. The objective of several US studies was to assess the impact of changes to insurance coverage on avoidable and overall admissions. National US data showed a reduction in inpatient activity, including a decrease of 7.8% in national hospital discharges among 15-17 year olds between 2000 and 2007, and a 15.8% decrease in pregnancy and delivery discharges.(222) This trend was consistent with more in-depth studies in Florida (217) and New York State.(225)

Changes in the nature of admissions were also noted, with a reduction in paediatric surgical admissions noted in several countries. Data from New York State and older data from Switzerland (226) found a trend towards increasing psychiatric admissions in childhood and adolescence. This was found in our data for adolescent females in New Zealand but we found no change in New Zealand males and a marked reduction in inpatient psychiatric activity for adolescents in Australia and England.

Limitations

International comparisons are useful in providing wider context and validation of the English findings. However, it is important not to over-interpret these comparisons. Even between English, Australian and New Zealand data, which is coded using the same classification system and age bands, there may be significant differences in the methodology used and any differences should be interpreted with caution.

Additional caveats apply to the findings of the scoping review. Firstly, this was not performed with the rigour of a full systematic review, searching only one database, making no use of synonyms or MESH terms, and using only one reviewer. There is potential for this to have introduced bias against studies that address similar issues but use different terminology or have not been published in Medline listed journals. Similarly, the lack of a second person to review all the abstracts increases the risk of error or subconscious bias when identifying publications of interest.

Secondly, there is likely to be wide variation in coding and categorisation systems between countries. To take one example, the diverging trends in inpatient mental health activity may reflect different classification of learning disabilities, which are aggregated with psychiatric admissions in the English HES data.

Conclusions and policy implications

These data link to two very topical policy areas in England. The national Children and Young People's Health Outcomes Forum (62) has recommended that all inpatient and wider data on young people be made available in 10-14 and 15-19 age bands, allowing meaningful assessment and comparison of many adolescent outcomes for the first time. At the same time, the national quality standards for adolescent services, published by the Department of Health last year have been recently validated for inpatient and ED services (see sections 4.4 - 4.5 and 7.2 - 7.3), providing an evidence-based tool for service improvement.

8.2 Health inequality trends among English children and young people.

The analyses of inequality trends, (presented in sections 2.6 and 5.6) extend previous inequality research to a range of outcomes which are most meaningful to young people themselves. These data show a consistent trend towards increased health inequality in younger children between 1999 and 2009, including parent/carer-reported general health, presence of a longstanding illness, obesity and episodes of hospital care. A similar trend was seen for smoking among young adults, which showed a significantly stronger association with deprivation in 2009 than in 1999.

Health Survey for England (HSE) data showed a non-significant trend towards greater inequality in all outcomes studied among adolescents and young adults. The consistency be an association my data were underpowered to detect. In contrast, inequality for inpatient activity decreased in older children and adolescents, with a particularly marked reduction in females aged 15-19.

Strengths and limitations

A strength of this study is the use of nationally-representative data collected in a consistent way across ten years of the previous government's strategy to reduce health inequalities. Unlike infant mortality, in which inequality has decreased slightly over the past decade, these data highlight growing inequalities in morbidity and the experience of children and young people, who are often less visible in national data. (33) Behavioural risk factors are the leading cause of death in developed countries (227) and are largely acquired in this age group (24) Similarly, adolescence and young adulthood are a critical period for the emergence of lifelong health inequalities,(32) which are particularly topical at a time of high youth unemployment in England and across Europe. The findings are very relevant to current policy, suggesting a way in which the statutory duty to reduce health inequalities can be monitored, without the cost of establishing new data sources.

A limitation of the HSE analysis is the unequal numbers of participants between age groups, resulting partly from different weighting and interview protocols at different ages. The apparent greater increase in inequality among younger groups may partly reflect greater statistical power in these groups.

In common with other survey data, further limitations include

- the much smaller sample size than the routinely collected population data such as Hospital Episode Statistics, with resulting reduction in statistical power
- potential for bias due to different characteristics of those who agreed to take part in the survey and those who declined (see below for more detailed discussion of non-response bias).

Perhaps the major weakness of the HES analysis is the method for age-standardising activity data. Data on age-distribution within each deprivation decile were only available for 2010; any change in age-distribution between 1999 and 2009 could therefore have influenced our findings. This issue may be particularly important to address in the future if the welfare reforms result in large families being forced to move from social housing in expensive areas due to the cap on housing benefits.(228)

We are not aware of any previous studies that have analysed concentration indices of national level activity data. The concentration index is considered to be a better measure of inequality across a population than alternatives such as the absolute and relative range,(185) and has been previously used for comparison of inequity in healthcare activity. One study in 2006 showed the UK had the smallest pro-rich bias in use of specialist care among 22 OECD countries and a significant pro-poor bias in primary care activity.(229) As the English NHS has remained free at the point of use across the period of this study, changes in the concentration index are likely to reflect changes in the distribution of health need within the population. We chose to analyse inpatient activity as a more objective measure of healthcare need than self-referral services and because avoiding hospital admission was identified as a priority by young people themselves. We therefore believe this method can be a useful tool for monitoring inequality trends, as it uses routinely collected data and can be calculated conveniently at local, regional and national levels. However, the use and interpretation of concentration indices would clearly benefit from further development in different contexts in the future.

Conclusions and policy implications

Saxena et al (2002) reported no effect of social class on health status or use of health services among English children and young people aged 2-20.(86) The findings in Chapter 5 demonstrate that large differences between social classes have developed over the past decade, although this was more marked in younger groups. Concerted action may be needed to reverse current trends and meet the new statutory duties to reduce health inequalities. The current financial climate increases the urgency of tackling inequalities but also increases the challenge of securing the necessary resources, leading UNICEF to predict a major increase in English child poverty over the next decade if current policies continue.(230) Proposed changes to NHS resource allocation are also expected to transfer healthcare funding away from younger, more deprived areas to older, more affluent ones.(231) Part of the case for action is the moral argument discussed by Law et al. (232) who demonstrate that child health inequalities are avoidable and reflect greater injustice than adult inequalities, as children are not equally responsible for the determinants of their health. However, the case also rests on robust evidence and economic analysis, with Michael Marmot and others having demonstrated the costs of failing to address social determinants of health in the crucial early and adolescent years. (37) International evidence over the last two decades shows that effective policies can lead to sustained reduction in social inequalities affecting children and young people.(233)

From a research perspective, the both the HSE and HES findings deserve further investigation and are currently the subject of an ongoing project by the UCL Policy Research Unit. In collaboration with Steve Morris, Professor of Health Economics, this study will use concentration indices to compare multi-year trends in adolescent inequality across a range of indicators.

8.3 Young people's inclusion and reported experience in national surveys

The material in sections 3.4-3.5 and 6.1-6.2 provides the first comprehensive review of children and young people's NHS experience over the past decade. I found that the views of under 16s and their families have largely not been included in national surveys, contributing less than 0.6 % of survey respondents since 2001 and none since 2004. Young people aged 16-24 are included in surveys, but rate their care significantly lower than adults across all domains of emergency department and primary care and most domains of inpatient care.

Sir Ian Kennedy suggested that satisfaction should be the 'single criteria for measuring the quality of the NHS's services for children and young people,'(27) while the English Department of Health says that the principle of direct patient feedback 'is now standard among healthcare systems worldwide.'(89) Failure to listen to the views of under 16s is not an issue confined to England. We are not aware of any other country that has conducted systematic national surveys which look at young people's experience of healthcare. In many ways, the NHS has been a pioneer in this area, promoting both the voice of patients, through national surveys of adult patients, and the provision of 'adolescent friendly' services, which work in partnership with young people at local level. As our data show, NHS services are often good at listening to young people and at national policy level, there is a clear gap between our findings and the stated aims of professionals and policy makers to listen to young people. The UK is a signatory to the United Nations Convention on the Rights of the Child (1989) (UNCRC)(113) which states an obligation to allow children to express their views and participate in decisions affecting them. Although the government cites 'practical and ethical' difficulties in obtaining the views of children and young people,'(89) most experts believe these are overstated,(62) with a number of survey tools available to NHS Trusts and much support and guidance available.(234;235)

National data from other countries on the experience of young adults are also very sparse, despite increasing recognition of the importance of this age group for population health, and of their specific healthcare needs.

Patient feedback as a measure of healthcare quality

Key determinants of young people's satisfaction with health services include the ability to listen to and engage them, build confidence and trust, treat them with respect and dignity, and uphold confidentiality.(4) We chose to analyse four questions from the surveys which best matched these concerns.

Patient perceptions are widely regarded as the best source of information on many aspects of care. Previous research has shown the importance of asking young people themselves,(236;237) as their perceptions differ from those of their parents, particularly relating to perceived involvement in care, communication and confidentiality.(238) Young people's satisfaction is largely based on provider behaviour and predicts young people's intention to return for follow-up appointments.(239)

However, patient satisfaction clearly has a subjective component and it may be influenced by psychosocial factors.(240) Where groups have different expectations of healthcare, this may also influence their satisfaction rating. For example, a British study found that South Asian adults were less satisfied with the time they had waited than those from other ethnic groups, despite adjusting for their actual waiting time.(241)

Lastly, there is potential for the findings to be distorted by lower response rates among specific patient populations. Previous research by the Picker Institute has shown marked differences in questionnaire response rates between different patient groups; in particular, questionnaires are less likely to be completed by more marginalised groups, including patients with lower income, lower educational attainment, and those belonging to black and minority ethnic groups.(242) In our study, it was notable that response rates were lower among young people than over 25s, and our findings may therefore underestimate the degree of difference between young people and older adults.

The lack of comparable outcome data makes it difficult to compare objective healthcare quality for different age groups. The over 25 age group itself is far from homogenous and the quality of services for elderly people is high on the political agenda. However, the lower satisfaction of young people is consistent with the Kennedy report's findings that services for this age group are frequently 'mediocre', as well as international comparisons which have raised concern about the quality of NHS services for children and young people.(72)

Lastly, standardised questionnaires provide little information about why 16-24 year olds might be less satisfied than older adults. Previous work suggests that a poor experience of transition and difficulty adapting to adult services may be important factors, especially in those with a long term condition.(27) However, these data do not allow us to explore the reasons for lack of satisfaction any further.

Strengths and limitations

This is the first study to examine systematically the evidence of young people's inclusion in national surveys and their experience of healthcare services. It is based on a comprehensive review of national studies by the Department of Health,(243) showing the priorities of policy makers and funding bodies over the last 10 years. All are high quality studies, with robust methodologies and large sample sizes, providing a reliable guide to patient experience across the NHS.

Analytic limitations largely relate to data availability. I was unable to adjust for the experience of older patients at the same trust (i.e. to test whether hospitals serving a young population tend to deliver lower quality care to everyone). However, even if true, this would mean that the NHS as a whole delivers poorer care to young patients than to older people. There were also specific limitations related to the analysis of each dataset.

The public datasets of the Emergency Department (2008) and Inpatient (2009) Surveys do not include a variable or weighting factor for the NHS Trust where the patient was treated. Unlike some previously published analyses of inpatient data,(30) no such factor was therefore included in our model. As these are national data, from standardised sampling in every relevant NHS trust, there is minimal risk of sampling bias at organisation level, but there may be small effects due to different response rates between trusts. For Young Patient (2004) and Adult Inpatient (2004) analyses, we were comparing across two different datasets. Therefore, our findings could not be adjusted for the presence of a long term condition or for the different sampling probability of subjects from different centres (as has been done in one previous published analysis of the Young Patient Survey).(30) The dataset for the GP Survey (2009/10) is not publicly available and our analysis was therefore based on the published commentary report and technical annex. This prevented analysis by sex or adjustment for the presence of a long term condition.

Conclusions

The views of children and young people under 16 are given disproportionately little weight within the NHS. Although the majority of young people aged 16-24 are satisfied, they consistently report poorer experience of care than older adults. These findings are consistent with a range of expert opinion (27) and qualitative research with young people,(244) supporting the view that 'the NHS is designed by older people for older people.'(27)

To meet the challenges of the Kennedy Report and the UNCRC, policy makers, clinicians, commissioners and managers should ensure that young people's views are heard, building on the success of recent initiatives to improve services for young people.(245) Further research is needed to guide this process – both qualitative work to understand better young people's experience of healthcare, and quantitative work to improve the quality and quantity of survey data.

8.4 Young patients' priorities and wider patient experience

Extensive research in England and other countries has explored and documented what young people value in healthcare services. However, little work has those of older people. To our knowledge, the research presented in sections 3.3 and 6.3 represents the first attempt to address this question using national level data.

The findings extend the preceding discussion (section 8.3) and show that young adults report a poorer experience of care than older adults across all key inpatient domains. Without improvement in this experience, many young people will continue to disengage from healthcare services, with serious long-term consequences for population health and use of health services.(24) The correlation of different experience domains with overall satisfaction may be useful in guiding improvement strategies. Young women report low scores for being treated with respect and dignity and the skills/attitudes of their doctors, while these domains correlate more strongly with their overall rating of care than in other groups. Young men report a poorer experience than older men across all domains but effective pain control shows a particularly strong correlation with overall satisfaction in this group.

Perceived lack of respect may be related to negative societal attitudes towards young people in Britain,(12) reflected by a young person in one *You're Welcome* consultation group whose main request was to be treated 'by people who like us' (ref JCRPE). In other cases, it may relate to the provider characteristics identified here and in previous literature as critical determinants of young people experience of healthcare.(105) An Australian study found a significant proportion of doctors felt uncomfortable talking to young people. Both doctors' confidence and young people's ratings of their consultation skills improved significantly following a brief training intervention.(246)

With these exceptions, these data show little variation in patient priorities by age. It is unlikely that this is due to insufficient age difference between the groups, as over half (50.8%) of the 25+ group were aged 66+, and the vast majority (96.8%) were aged at least 36.

Strengths and limitations

A strength of this study is the large, nationally representative sample which allows age-stratified analysis of different domains of care. Although young adults made up a small proportion (3.2%) of overall respondents, this still represents a large sample of young people which show statistically significant differences in patient experience and

priorities by age.
In common with all analyses of survey data, this study cannot explore the reasons for poorer reported experience among young people. As discussed in Chapter 8.3, survey responses are influenced by patient expectations and other factors as well as care quality.(214) Similarly, the second half of the analysis simply indicates which aspects of care are most strongly correlated with overall satisfaction in this population. Pain control might be more strongly correlated with satisfaction in young men because healthcare staff are less attentive to their needs, because they have lower pain thresholds than older men, or simply because a higher proportion is admitted with painful injuries or illnesses.

We suggest that these findings will be of most use to service providers when interpreted in conjunction with the extensive qualitative literature into young people's experience of healthcare services and, most importantly, the views of young people using their service. A further weakness is that the data do not allow direct comparison of perceptions about confidentiality, although this issue is partially included in ratings of provider characteristics and privacy.

Conclusion
Overall care rating and experience in 8 domains of care were poorer for young women than for any other group. Young men also report a poorer experience of care than older men on every indicator. When compared to older adults of the same gender, young men's satisfaction was more strongly correlated to pain control, and young women's satisfaction was more strongly correlated with perceived respect and dignity and the skills and attitudes of their doctors.

In England and elsewhere, the voice of young patients is often not heard, either because they are outnumbered by older patients or they are simply never asked their views. It is hoped that these national-level quantitative data will contribute to the process of improving health services for young people, by encouraging dialogue between service users and providers.

8.5 You're Welcome validation in inpatient and Emergency Department settings

To our knowledge, the material presented in sections 4.4-4.5 and 7.1-7.2 constitutes the first use of national data to validate a quality improvement tool for inpatient and emergency adolescent services. A validated tool to assess and benchmark inpatient services for adolescents is particularly important in view of the increasing numbers of hospital admissions in young people.(247) (see also section 5.4). Similarly, the reliance of many young people, especially young men, on emergency services mean that high-quality age-appropriate services for them are essential.(27;82) (see also section 5.1).

Although limited by lack of data on the criteria addressing access, publicity and confidentiality, the findings in section 7.1 provide strong support for the face validity and content validity of the remaining *YW* quality criteria (4) in inpatient settings. Of 29 questionnaire items which matched *YW*, 28 were significantly associated with overall satisfaction. The *YW* criteria include 9 of the 10 questionnaire items most strongly related to overall satisfaction in the Young Patient Survey and 10 out of 10 in the adult Inpatient Survey. Similarly, the data in section 7.2 strongly support the face validity and content validity of the *You're Welcome* quality criteria for young adults in emergency department settings (although they are again limited by lack of data on the criteria addressing publicity, confidentiality, and involvement of young people). Of 16 questionnaire items which matched *You're Welcome*, all were significantly associated with overall satisfaction. The majority of questionnaire items that correlated most strongly to overall satisfaction were included in the *You're Welcome* criteria. Those that were not explicitly mentioned refer to provider characteristics which in general are heavily emphasized in the *You're Welcome* approach.

Details of the inpatient and ED analyses are now discussed in turn.

Inpatient validation

The WHO and much research literature have focused on adolescent friendly primary care services, despite the importance of hospital care for the most common causes of adolescent mortality and morbidity. A validated tool based on WHO standards has now been published for primary care services – the YFHS-WHO+ Questionnaire.(35) However, hospital services have received much less attention, despite the increasing numbers of hospital admissions in this age group (see Chapter 5) and the importance of hospital care in addressing the major global causes of mortality and morbidity.

The philosophy of *YW* rests on meaningful participation of young people in monitoring and improving services. While young people should certainly be included in patient surveys,(214) wider efforts to promote their participation in all aspects of organization and development of health care are needed. (59)

Young people and their parents have been reported by several authors to rate provider characteristics as more important than aspects of the physical environment or process issues.(105;106;248) Our data support these findings, with questions related to staff training, skills, attitudes and values correlating most strongly with overall satisfaction. There is evidence of the benefits of training in adolescent health (108) and a range of resources are available for professionals wishing to develop their knowledge and skills in adolescent health.(249;250)

Strengths and limitations

I used large, nationally representative surveys which have face and construct validity,(251) use standardized methodology and have been the focus of extensive previous research. As discussed in Chapter 8.3, survey responses by patients often have a subjective component and may reflect differing expectations as well as differing quality of care. The Picker Institute surveys are designed to mitigate these effects, differentiating between subjective measures of satisfaction and more objective reports of patient experience. Patient feedback is also recognized as the only valid source of information on some aspects of care quality, such as feeling treated with respect and dignity.(252) The broad consistency in young people's feedback between the *You're Welcome* criteria (themselves the result of extensive consultation) and separate analyses of three patient surveys supports their validity. This is reinforced by their very different origins: the patient survey questions were adapted from questionnaires developed with adult patients while the *You're Welcome* standards represent a consensus from groups of young people and professionals over many years of consultation.

The major weakness of the inpatient study is the lack of any survey questions relating to accessibility, publicity, confidentiality or consent (*You're Welcome* Criteria 1-3). There is also no direct reference to adolescent health screening (included in Criteria 8). The criteria are intended to be comprehensive and applicable to all health services for young people and it may be unsurprising if some criteria are more relevant in a particular context. A recent outpatient survey found that waiting times and pre-appointment information were two of the most important issues for young people.(91) However, although the related issue of privacy is covered well in the surveys, the absence of data on confidentiality is a significant weakness. A clear explanation of confidentiality and the opportunity to see a doctor (or health professional) alone were highly valued by young inpatients during the *YW* consultations.(253) Although confidentiality is an issue for adults, it is well-documented as causing particular concern for young people in a range of settings,(57;244) particularly those who are most vulnerable.(254;255)

A related issue is the response rate, which is particularly low in the adult Inpatient Survey. As discussed above (see section 8.3) it is likely that non-responders will include many of the most vulnerable young people and this may include many of those with the poorest experience of hospital care.(242) A major reason for initiating the *You're Welcome* programme was to address health inequality(66) and the criteria were initially developed and piloted in work with small groups of marginalised young people, including those in local authority care, those with long term conditions and users of sexual health services.(56) Although higher response rates would make our findings more robust, this study complements those consultations well, validating the criteria using data from large numbers of young people drawn from the general patient population.

Although low response rates, particularly among young men, are common in many national surveys, design of future surveys involving young people should consider how best to reach and engage this age group – for example using computer-based rather than written surveys.(256)

Correlations between individual questionnaire items are known to be affected by their proximity in the survey and are subject to more variation than composite measures which aggregate several questions into a common domain.(213) However, as our purpose was purely to identify important factors missed by *You're Welcome*, rather than detailed analysis of their relative importance, we did not go on to correlate by domains of care or perform factor analysis to group the responses further.

Emergency Department validation

Many of the points discussed above are also relevant to validation of the *You're Welcome* criteria in ED settings. As shown in section 5.1, young adults account for a large proportion of ED, attend more frequently and report the poorest experience of any age group. More deprived young people are disproportionately likely to attend EDs (see Figure 12 in chapter 5.1), making it a key vehicle for health promotion messages, especially among males and the most marginalized groups that are less likely to be registered with or attend a GP surgery.(27) Opportunistic health promotion has been a major focus of the 'Future forum' led by Professor Steve Fields on behalf of the Department of Health.(257) International evidence further supports its value among young people. For example, young adults have the lowest rates of insurance coverage and opportunistic interventions in Emergency Departments provide an important safety net.(24)

Another important feature of the ED validation is the extension to young people in their early twenties. Although originally intended for adolescents aged 11-19, (following the upper age boundary of the National Service Framework for Children)(46), our data confirm previous findings that the care of young adults aged 20-24 shares many challenges with that of older adolescents.(258) Although the *You're Welcome* criteria have previously been used by services for those up to the age of 25, (104) this study is the first to validate its use in this age group, as well as the first to validate its use in an ED setting. In addition to research literature, the extension to include young adults up to their mid-twenties is also supported by the Kennedy report,(27) and current Department of Health guidance which suggests that a limit of 24/25 may be more appropriate for those with complex needs.(53;259)

Young people and their parents have been reported by several authors to rate provider characteristics as more important than aspects of the physical environment or process issues.(105;106;260) Our data extend these findings to the ED environment and a population of young adults aged 16-24. Questions related to staff training, skills, attitudes and values correlated most strongly with overall satisfaction. As noted above, there is evidence of the benefits of training in adolescent health (108;109) and a range of resources are available for professionals wishing to develop their knowledge and skills in adolescent health.(261;262)

Strengths and limitations

As in the inpatient validation, this study used data from a large, nationally representative survey which has face and construct validity,(263) and uses standardized methodology. Similar comments relating to the interpretation and validity of these findings apply. As before, a weakness is the lack of survey questions relating to some aspects of *You're Welcome* – in this case publicity, confidentiality and involvement of young people in monitoring service quality. There is also no direct reference to the opportunistic health screening discussed above. The importance of these omissions varies considerably. Emergency Departments are usually well-known by local communities so publicity may be a less significant issue in this context. However, as for inpatient services, the absence of data on confidentiality is a significant weakness. Future research should address these issues and attempt to validate all of the *You're Welcome* criteria. The addition of relevant questions to the national patient survey questionnaires would improve their validity as a measure of adolescent ED experience, as well as facilitating future research.

The response rate again deserves mention - being around 40% overall and even lower in younger groups. It is likely that non-responders will include many of the most vulnerable young people and many of those with the poorest experience of emergency department care, although similar arguments apply that survey respondents may complement well the very marginalized groups who contributed to the early iterations of *You're Welcome*.

Conclusions

In summary, data covering the majority of *YW* criteria show that they function well as a measure of quality for adolescent inpatients and young adults in Emergency Departments. Provider characteristics are more important predictors of young people's satisfaction with care than facility or process characteristics. In addition to validation of the publicity, confidentiality and participation criteria, further work is needed to validate the *YW* criteria outside the UK and investigate whether youth friendly health services influence health outcomes outside of satisfaction and rating of quality.

Chapter 9. Conclusions and implications for future policy and research

In common with all aspects of health policy, the future of adolescent health services in England will be heavily influenced by the ongoing NHS reforms. As described above, the Children and Young People's Health Outcomes Forum (CYPOF) submitted a report to the Secretary of State in July 2012, shortly before the submission of this thesis. This contained a comprehensive set of recommendations about the future research and policy agenda to improve the health of children and young people in England This final chapter summarises some of the key implications of findings in this thesis for future policy development and research strategies.

Collection and analysis of healthcare activity data in adolescents

The activity data presented in Chapter 5 start to address the information gap about health service activity in adolescence that has been identified by UNICEF, Kennedy and others (see sections 1.1-1.2). It is hoped that this will support efforts to raise the profile of adolescent health among policy makers and those responsible for post-graduate education of medical, nursing and paramedical professionals across all relevant specialities.

The Children and Young People's Health Outcomes Forum (CYPOF) recommended that in future, all NHS data is collected in 10-14 and 15-19 age bands, to facilitate international and local comparison. The national data presented here may provide a useful reference point for local areas wishing to place their results in context, contributing to the process of planning and commissioning services.

Monitoring and addressing health inequalities

Section 8.2 concluded with a number of important points about health policy, including:

- Significant differences between social classes in the health of young people have developed over the past decade, although this has been more marked in younger groups.
- Concerted action may be needed to reverse current trends and meet the new statutory duties to reduce health inequalities. The current financial climate increases the urgency of tackling inequalities but also increases the challenge of securing the necessary resources, leading UNICEF to predict a major increase

in English child poverty over the next decade if current policies continue.(230)

- Proposed changes to NHS resource allocation are also expected to transfer healthcare funding away from younger, more deprived areas to older, more affluent ones.(231)

Regarding inequality in self-reported health and lifestyle factors, the first priority is to ensure that this continues to be monitored at national level, in order to hold the Secretary of State accountable for his legal duties. Lack of adequate data mean that the accountability of local commissioners for health inequalities may be difficult to enforce, unless greater resources are available for large-scale surveys.

The association between deprivation and healthcare activity is likely to become increasingly important with the increasing policy focus on unwarranted variation in healthcare activity. Although the authors of the original Dartmouth Atlas series in America estimate that only around 4% of variation is due to poverty,(183) data on children and young people in England suggest that deprivation may explain a larger degree of variation in some settings.(264) Further research into the mechanism of individual and community measures of deprivation, and the size of their effect on health service activity, is an important priority in order to guide the use of variation data in reducing costs and improving healthcare quality.

As noted above, some of these issues will be investigated in an ongoing project by the UCL Policy Research Unit. In collaboration with Steve Morris, Professor of Health Economics, this study will use concentration indices to compare multi-year trends in adolescent inequality across a range of indicators.

Promoting the voice of young people in health services

The findings in this thesis provide support to some aspects of the current NHS reforms. For example, the approach of ‘No decision about me without me’ fits well with the views of young people in the *You’re Welcome* consultations presented in section 8.5. The Children and Young People’s Health Outcomes Forum has recommended that this approach is applied to children and young people, and that they are fully involved in future patient surveys and patient involvement processes.(62) However, the policy arguments would be strengthened in the future if researchers are able to show firmer links between participation and engagement of young people and clinical outcomes.

Age appropriate care and adolescent friendly services

The policy and research literature has sometimes given the impression of mixed messages about the provision of dedicated health services for adolescents. Specialists have argued for many years that multi-disciplinary teams within adolescent centres provide the highest standards of care, especially for management of the most challenging young people. As a result, places that have insufficient resources or volume of adolescent activity to justify dedicated services sometimes receive a message that nothing worthwhile can be done to improve adolescent services. In fact, provider characteristics are consistently identified in the literature and in Chapters 6 and 7 of this thesis as the most important aspects of care for young people. At national level, young people are likely to benefit more from better universal training in communication skills and adolescent health than development of a few isolated centres of adolescent health excellence.

This thesis largely uses national data and so does not address the question of dedicated adolescent services directly (with the exception of a brief discussion in section 8.5). However, both the consultations discussed in section 8.5 and the quantitative data support the emphasis on young people's involvement and staff training as key determinants of service quality. Specialist services clearly have an important part to play in the national system, both in managing the most challenging clinical cases, and in training generalists wishing to develop an interest in adolescent health. Several of the *You're Welcome* project sites found creative solutions that provided at least some dedicated facilities for young people and this trend is likely to continue wherever young service users are able to participate in service design and reconfiguration.

The CYPOF report provides some indications of how child and adolescent health policy may develop in the future. One trend is a broadening of the concept of young people friendly services (sometimes perceived as focusing purely on patient experience) towards an emphasis on age appropriate care. This wider concept also incorporates safety issues related to insufficiently trained staff or inappropriate care environments, and key clinical outcomes for this age group – for example self-management of long term conditions, or acceptable disease control during transition to adult services.

It is not yet clear what the Government's future approach will be to the *You're Welcome* standards. They received strong support from the CYPOF report and remain Government policy, although they have not been widely promoted in recent months. However, the existence of a validated tool provides an evidence base for future initiatives.

The CYPOF co-chairs met with many groups who regarded their advocacy for children and young people as a form of 'special pleading' (Personal communication: Ian Lewis and Christine Lenehan at Forum meetings, 2012). The forum's report aims to ensure that the voice and needs of young people are given equal weight to those of adults, and their distinct needs are met. It is hoped that material in this thesis contributes in some way to a future health service which better understands and meets those needs.

Afterword. Lessons from the MD (Res) process

The original research proposal for my MD (Res) degree, submitted in December 2009, stated that I would investigate the relationship between adolescent-friendly services and clinical outcomes. As described in sections 4.1-4.3, I was the clinical and research lead of a national project to revise the *You're Welcome* criteria for young people friendly services. Between September 2009 and April 2010, this ran as a collaboration between 16 project sites, the Department of Health, the Young People's Health Special Interest Group of the Royal College of Paediatrics and Child Health, and a number of other national and local organisations. It was envisaged that analysis of project data would provide the main focus of my MD research.

This project had mixed results, with successful publication of revised *You're Welcome* standards in April 2011, but withdrawal of the original evaluation process due to lack of agreement among the project partners. *This material is therefore not included in the thesis.*

My other main research focus during 2010 was analysis of the Healthy Foundations dataset, collected by Ipsos Mori on behalf of the Department of Health in 2008. This work was a good introduction to use of logistic regression and other techniques in SPSS and has led to a useful ongoing collaboration with Dom McVey and Prof Agnes Nairn who were involved in setting up the study. However, following my upgrade viva in February 2012, it was agreed to focus more clearly on health services and the Healthy Foundations research has therefore been omitted from the final thesis.

Moving from the Department of Health, I have sometimes felt a tension between the demands of a policy perspective, which often emphasises the wider context around adolescent health services, and the depth required for robust research. In this thesis, I have tried to combine scientific rigour in the analyses with a discussion of their policy implications. In doing so, I have been very grateful for the advice of Russell Viner, Ruth Gilbert, John Coleman and many others but retain the responsibility for any failings.

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Appendix