Welcome

This summary of AYPH's latest Research Update focuses on long-term conditions. We produce these regular updates to provide an overview for our members of current research, and to highlight recent policy developments concerning adolescent health. Topics covered by earlier updates include Accidents and Injuries, Health Inequalities, Disability, Physical Activity, Alcohol & Substance Use, Teenage Pregnancy & Sexual Health, and Mental Health & Emotional Wellbeing.

This summary includes 12 items from the main update and also gives details of the additional articles in the full version. You can obtain the full version along with copies of all our past and future updates by joining AYPH. Other member benefits include a monthly newsletter, additional resources in the member’s only area of our website, free copies of our flagship publication - Key Data on Adolescence - and discounts for our annual conference and other events.

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Introduction

This Research Update provides an overview of long-term conditions affecting adolescents. It complements an earlier update on Disability that we produced last April and covers a selection of recent reports and research, as well as the latest data and policy guidance.

Long-term conditions that cannot be cured are a highly significant concern for growing numbers of young people and their families. They also present very major challenges for health service professionals and others involved in providing age-appropriate treatment, care and support.

Results for England from the latest HBSC1 study found that 15% of all school students aged 11-15 report having been diagnosed with a long-term illness, disability or medical condition. This increasing prevalence of long-term conditions has led to greater attention being focussed on them, with the new NHS Outcomes Framework including an indicator on reducing unplanned hospital admissions in under-19s for asthma, diabetes and epilepsy.

Despite the publication of extensive guidance, many of the articles included here show current provision to be generally falling some way
short of best practice models. Similar concerns are evident in relation to transition planning which now takes on even greater significance as enhanced treatment strategies have led to substantial improvements in life expectancy for young people with life-limiting conditions. Improving services for young people with long-term conditions must therefore remain a key priority for reformed health services. This is not just essential for their immediate quality of life. Establishing good health management in adolescence can help those affected to manage their condition far more effectively over their whole life course. This should also help to reduce demands and service costs in the longer term.

**Latest data on long-term conditions**

Statistics on the prevalence of selected long-term health conditions

**Asthma**
- Around 1.1 million children and young people (1 in 11) in the UK have asthma, making it the most common long-term medical condition.
- On average, there are two children with asthma in every classroom, with the UK having one of the highest prevalence rates of asthma symptoms for children worldwide.
- 1 in 8 children with asthma symptoms experience attacks so severe that they can't speak.
- The number of hospital admissions in England among 10-19 year-olds because of asthma has increased by 27% since 2002/3 to just under 8,600 in 2009/10.
- An estimated 75% of hospital admissions are preventable - and people without an asthma action plan are four times more likely to have an attack requiring emergency hospital treatment.

**Cancer**
- Around 1 in 500 children in the UK develop some form of cancer by the age of 14, making it the most common cause of death from disease for children and young people.
- Nearly 950 adolescents aged 10-19 were diagnosed with cancer in England in 2008.
- Rates for newly diagnosed cases (per 100,000 population) are higher among males and increase with age across the whole life course - in 2008, from a rate of 13.2 among boys aged 10-14 to 30.5 for young men aged 20-24.
- Improved treatment strategies have led to substantial increases in survival rates for childhood cancers over the past 40 years - nearly 8 out of 10 children diagnosed with cancer now survive for at least five years, compared with fewer than 3 in 10 in the late-1960s. However, five-year survival rates for leukaemias are 25% higher for children aged 0-14 at diagnosis than for older adolescents and young adults aged 15-24.
**Diabetes**

- Around 29,000 children and young people in the UK have diabetes, with about 26,500 of them having Type 1 diabetes, 500 having Type 2 diabetes, and a further 2,000 with diabetes whose diagnosis is unknown.
- The current estimate of prevalence of Type 1 diabetes in the UK is 1 per 700-1,000 children and young people, with the peak age for diagnosis being between 10 and 14 years of age.
- The number of hospital admissions in England among 10-19 year-olds because of diabetes has increased by 31% since 2002/3 to just under 7,600 in 2009/10.
- Type 2 diabetes is now being diagnosed more frequently in younger overweight people and is most prevalent among children and young people of South Asian origin.
- Obesity accounts for 80-85% of the overall risk of developing Type 2 diabetes and underlies the number of people diagnosed in the UK doubling from 1.4 million in 1996 to 2.9 million today. Latest forecasts suggest that over four million people will have diabetes by 2025.

**Epilepsy**

- Some 600,000 people in the UK have epilepsy - around 1% of the population - with young people under 18 accounting for around 10% of this total.
- There were just over 5,400 hospital admissions among 10-19 year-olds in England for epilepsy in 2009/10 - an increase of 19% since 2002/3.
- Many adolescents with epilepsy will ‘grow out of it’ in adult life.

**Recent reports**

The selection of reports summarised below highlights a key issue for young people’s health - that specific information on the particular health needs of adolescents and the issues they face is very often unavailable. While official statistics and most research tends to include younger adolescents in a broader group of children and young people aged 0-15 or 5-15 years, the interests of older adolescents aged 16-19 are also frequently lost among the wider information generally produced for broader adult age groups.

**Missing Out - Asthma UK, May 2009**

http://asthma.org.uk/document.rm?id=751

This report summarises the findings of Asthma UK’s research into what it is like for children and young people to live with the condition. It focuses on everyday issues they deal with and how these can mean them missing out or being excluded from essential opportunities and experiences. The study employed a mixed methods approach which included focus groups and quantitative research with children and young people with asthma, as well as a representative sample survey of over 1,600 teachers.

The key findings and showed that:

- nearly half of children and young people with asthma had problems in joining in with general lessons, with a similar proportion having problems going on school trips
- the real difficulties children and young people with asthma experience at school stemmed largely from the lack of training and understanding of teachers, particularly in secondary schools
- such lack of understanding contributes to many children and young people with asthma missing out on sports or PE, with nearly three-quarters having problems joining in with PE lessons
- many children and young people with asthma are not achieving the physical activity levels needed to maintain or improve their health - and being seen as different by other children also increases the potential for bullying.
Asthma UK makes a number of recommendations for addressing these issues and to increase recognition and understanding of asthma in schools. It advocates all schools developing a policy to support children and young people with asthma, and also argues for the development of a set of consistent standards for asthma services (based on its own Good Asthma Services Checklist) to tackle existing inequalities.

Growing up with diabetes: children and young people with diabetes in England - Royal College of Paediatrics and Child Health, March 2009
http://www.rcpch.ac.uk/sites/default/files/asset_library/Publications/G/Growing%20up%20with%20Diabetes%20FOR%20WEB.pdf

This survey was commissioned by NHS Diabetes to find out how many children and young people in England have diabetes, as a first step towards making necessary improvements in health care and provision. Among the key findings, the research established that:

- there were just under 16,300 adolescents aged 10-17 with diabetes in England in January 2009, with 96.5% having Type 1, 2% having Type 2 and another 1% having other types of diabetes
- 77% of children and young people with Type 1 diabetes are over 10 years of age, as are 98% of those with Type 2
- while the overall diabetes prevalence rate for all children aged 0-17 in England was 209 per 100,000, there was substantial variation between regions with the prevalence rate ranging from 137 in the East Midlands to 280 in the North East.

### Type of diabetes in England by age category

<table>
<thead>
<tr>
<th>Age</th>
<th>Type 1</th>
<th>Type 2</th>
<th>Other types</th>
<th>Total</th>
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<tr>
<td></td>
<td>Number</td>
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<td>Per cent</td>
<td>Per cent</td>
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<td>0-4</td>
<td>827</td>
<td>0</td>
<td>31</td>
<td>858</td>
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<td>4.0</td>
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<td>5-9</td>
<td>3,920</td>
<td>6</td>
<td>34</td>
<td>3,960</td>
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<tr>
<td></td>
<td>19.1</td>
<td>1.8</td>
<td>10.6</td>
<td>18.7</td>
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<tr>
<td>10-14</td>
<td>8,715</td>
<td>128</td>
<td>114</td>
<td>8,957</td>
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<tr>
<td></td>
<td>42.5</td>
<td>39.1</td>
<td>35.6</td>
<td>42.2</td>
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<tr>
<td>15-17</td>
<td>7,026</td>
<td>194</td>
<td>141</td>
<td>7,361</td>
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<tr>
<td></td>
<td>34.3</td>
<td>59.1</td>
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<tr>
<td>Total</td>
<td>20,488</td>
<td>328</td>
<td>320</td>
<td>21,136</td>
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In summarising the current state of diabetes care, the report makes a number of key recommendations and solutions for improving services focused on:

- prevention and early identification (of Type 2 diabetes)
- tackling barriers to supported self management
- developing integrated, seamless services (with the active involvement of service users)
- reducing inequalities in access to specialist provision, and tackling discrimination in and out of work.

The report includes a dedicated chapter on children and young people with diabetes and highlights unacceptable variations in the level of support to help children and young people manage their diabetes in school and in access to healthcare. The research found that too few children and young people received all the care processes they need to manage their condition, and that more needed to be done to improve experiences of the transition process from paediatric to adult services. Diabetes UK has subsequently developed a Children’s Charter (with the involvement of children and young people with diabetes, their carers and healthcare professionals).

Evaluating self-care support for children and young people with long-term conditions - Kirk S, Beatty S, Callery P, Milnes L and Pryjmachuk, University of Manchester, August 2010
http://www.sdo.nihr.ac.uk/files/project/162-final-report.pdf

In this report produced for the National Institute for Health Research, the authors contend that childhood long-term illness has been largely overlooked in policy and research relating to self-care, and that little is known about the efficacy of different self-care models for young people. Also, with the main focus of self-care interventions for this group so far having been on disease management and information provision, the psychosocial aspects of living with a long-term condition has received less attention.

The objectives of the study were to:

1) describe the range and type of self-care support models for young people with long-term conditions
2) evaluate the success of different models of self-care from different perspectives
3) identify the factors which serve to promote or inhibit self-care
4) investigate how professionals can best support self-care for children and young people.

The study focused on four conditions which differ in terms of the complexity of self-care management, prognosis and potential for the involvement of different NHS and non-NHS organisations - asthma, diabetes, cystic fibrosis and attention deficit hyperactivity disorder.

As the first study of its kind to evaluate self-care support for children and young people across different long-term conditions and across different models, the authors have reviewed and synthesised evidence from both qualitative and quantitative studies. Together with a national mapping exercise and six case studies, this enabled them to develop a typology that provides a framework for characterising self-care support models - summarising what works, how, for whom and in what circumstances, leading to a number of recommendations for both further research and for developing future policy and practice.

In emphasising the importance of self-care support programmes, resources and tools being developed to meet individual needs, the authors identify key elements that need to underpin such a ‘menu’ of choices:
• Patient-centredness - involving young people and parents in developing and evaluating projects; being sensitive to individual differences (such as disability, socioeconomic status, culture, age and gender); being aware of the young person’s experience of their illness and the wider context of their lives; taking account of the young person’s readiness to engage with self-care support; focusing on the individual’s goals for self-care and their support preferences; and promoting independence.

• Encouragement of social support by providing mechanisms through which young people and their parents can develop a sense of community and belonging and build their social networks.

• Promoting learning and personal development to increase confidence and self-esteem - through information and skills training, the provision of role models and encouraging shared decision-making.

The authors endorse ‘e-health’ methods as a potentially effective and appropriate means of providing social networking or self-management support. They also highlight the need for improved joint working and integration of self-care support between the voluntary sector and national health services, as well as the need for health professionals and other workers to have the values, attitudes, knowledge and skills necessary to support self-care. Last, they point to the need for schools to improve their support for self-care - to ensure that children and young people with long-term conditions enjoy the same educational opportunities and activities as their peers, and are also supported in managing relationships with them.

Recent research

The summaries provided in this section focus more closely on the particular needs and interests of adolescents with long-term conditions. It touches on some of the main challenges young people face in living with and managing their condition as they grow and emerge into adulthood. Although by no means a comprehensive review, this selection of recent research (from an extensive literature) addresses some key issues - including: adolescent development, user preferences and perspectives; personal relationships and social identity; adherence to treatment; transition to adult services; and new forms of communication.

The Challenging Adolescent


Adolescents are medically, developmentally and psychologically distinct from children and adults. Although the authors recognise that many adolescent patients are communicative, adherent and capable, practitioners are often faced with young people who seem difficult to work with for a variety of reasons. However, all young people need empathetic health professionals with the necessary age-related and developmentally appropriate skills to look after them well and advocate for them as they grow up. The authors believe that the first step for such skills training must be to understand why some young people appear so challenging in the first place. Their article therefore examines which adolescents are most challenging to rheumatology professionals, and why they appear to be so.

In offering some practical responses, the authors draw on both rheumatology and the wider literature, seeing many issues as common to a much larger group of young people with long-term conditions.

With respect to potential solutions to the challenging adolescent, the article underlines the importance of:

• treating young people with honesty and respect
• giving assurance of confidentiality
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- bracketing - setting aside our usual assumptions, biases and prejudice
- building trust through continuity and consistency
- giving young people the space and time to be seen independently from their parents and not to feel rushed
- effective, developmentally appropriate communication skills
- assisting as well as asking - supporting young people to deal with issues or problems
- making young people feel welcome.

“What we want”: chronically ill adolescents’ preferences and priorities for improving health care

This sequential mixed methods study focused on adolescents aged 12-19 years being treated in a university children’s hospital for various chronic conditions. It involved face-to-face interviews at home, hospital-based peer research, and a web-based questionnaire which generated 990 valid responses.

The researchers found that having ‘a feeling of trust’ and ‘choice and voice’ in the hospital were of central importance to young people with long-term conditions. The most important perceived qualities in providers were ‘being an expert’ and ‘being trustworthy and honest’; while ‘answering all questions’, ‘attending to my and my parents’ needs’ and ‘clear communication’ were the highest ranked preferences for outpatient consultations. In hospital, adolescents most wanted to ‘avoid pain and discomfort’, ‘keep in touch with home’ and ‘be entertained’. Their main priorities for improvement were paying more attention to older children, having more contact with family, friends and fellow patients, and shorter waiting times.

The authors conclude that adolescents with long-term conditions prefer technically competent providers, who are honest and trustworthy in attending to their needs. As they gradually outgrow the paediatric environment, they desire staff attitudes to become less childish and more age-appropriate, and welcome being treated as an equal partner in care. This requires health care professionals to inquire into adolescents’ preferences and to adjust their communication style accordingly. Their findings therefore lend further support to the potential solutions offered by McDonagh and Kaufman (2009) outlined above.

Improving the transition between paediatric and adult healthcare: a systematic review

Following the publication of Aiming High for Disabled Children and the establishment of the National Transition Programme (with funding to March 2011), there is now a potentially confusing proliferation of guidance on improving the transition between paediatric and adult care services. However, the transition process is still often poorly managed for young people with a chronic illness or disability, and this can result in adverse impacts on health as well as loss to follow-up.

Qualitative research has confirmed that many young adults experience the transfer to adult care as disjointed, and find it difficult to adjust to the associated increase in responsibility for their own care. Against this background, the authors conducted a systematic review of studies into transition programmes for young people aged 11-25 with chronic illness. Only 10 studies met the inclusion criteria of having consistently evaluated health outcomes - with six of these showing statistically significant improvements in health outcomes.

The authors identified three broad categories of intervention directed at: the patient (educational programmes, skills training); staff (named transition co-ordinators, joint clinics run by paediatric and adult
physicians); and service delivery (separate young adult clinics, out-of-hours phone support, enhanced follow-up). While the conditions involved varied, all six of the interventions that resulted in significant improvements were recorded in studies of patients with diabetes. It is not clear how generalisable these successful transition programmes in diabetes will be to other conditions. However, the authors conclude that existing evidence supports the use of educational programmes, joint paediatric/adult clinics and, also, clinics specifically for young adults.

**Current initiatives**

**NHS Atlas of Variation - November 2011**


The NHS Atlas of Variation has been developed as part of the Right Care programme which is focused on increasing value for patients and the commissioners of health services. It is intended to give clinicians and commissioners a fresh opportunity to identify and reduce unwarranted variation in the utilisation of health care services. Alongside the NHS Outcomes Framework, it is meant to act as a catalyst for driving improvements in quality, outcome and value throughout the NHS, and in tackling inequalities in outcomes.

The Atlas can be accessed in a number of ways - hard copy, downloadable PDF files and as an interactive online tool that presents a “dashboard” of related data, charts and maps for key indicators. A number of the 71 maps in the 2011 Atlas relate to long-term conditions. This includes two maps which present average information for 2007/8 - 2009/10 showing very wide variation between PCTs in emergency admission rates for children and young people (aged 0-17) with epilepsy (Map 20) and with asthma (Map 39).

**Epilepsy 12 National Audit - Royal College of Paediatrics and Child Health**


This 3-year audit is a partnership initiative being coordinated by the RCPCH with Health Quality Improvement Partnership (HQIP) funding. It aims to help improve patient outcomes by engaging health professionals to systematically evaluate their practice against key recommendations made in the NICE and SIGN epilepsy guidelines and to encourage improvement in the quality of care and services provided.

Nearly 90% of eligible units across the UK have now completed the Epilepsy12 Audit, submitting data for just under 5,000 patients. To date, more than 200 Patient Experience Questionnaires have also been completed by patients or their parents/carers. The final analysis of all the data will be carried out in April/May. Site specific reports and regional reports will be sent out in June. Individual units will receive an improvement toolkit and also be given support to review findings and action plan. Regional workshops will also be held prior to publication of the final audit report in September.
The latest data submitted by paediatric units for the National Diabetes Audit shows that, in 2009/10:

- episodes of diabetic ketoacidosis were more frequent in girls than boys, more common in teenage years and often recurrent - with large variation in recurrence rates between treatment centres
- although 89% of all children and young people with diabetes had a record of HbA1c measurement, only 4% of young people over the age of 12 had all the NICE key processes of care recorded
- less than 15% of the HbA1c measurements achieved the NICE recommended target, and over 30% of children and young people with diabetes were found to have a high risk for future complications.

Following the 2009/10 study, the Royal College of Paediatrics and Child Health has now been awarded three-year HQIP funding to take over the lead for the paediatric component of the National Diabetes Audit. The RCPCH aims to reinvigorate the national audit by introducing a number of innovations and efficiencies. These include introducing measures of patient experience and innovative approaches to data collection to minimise the burden on clinicians. The Royal College has reported 97% participation in the 2010/11 audit with 180 paediatric diabetes units submitting data for over 25,000 patients.

Children and Young People's Outcomes Forum
http://www.dh.gov.uk/health/2012/01/children-forum/

The Government has established a new Children's and Young People's Forum with a remit to maximise health outcomes for all children and young people and help them reach their full potential. The Forum of independent experts will meet regularly over the next few months, consult with key stakeholders, and make recommendations to Government on how the NHS can work best for children and young people.

The move has been widely welcomed by many organisations, including the Royal College of Paediatrics and Child Health and the National Children's Bureau, who have previously emphasised that the reforms of the NHS and the wider health system must give children a much stronger say in decisions about local services and their own individual health care. The Forum should help ensure that the needs of children and young people receive higher priority in the reformed health service, and is being viewed by some as an opportunity for making a step change in the way health services engage with children and young people and address their needs. It’s establishment comes soon after the submission of the NHS Future Forum's second phase report and recommendations to Government. This strongly emphasised the crucial importance of providing far more integrated care, organised around the needs of the patient, not the system - and recommended that every person with long-term or complex needs should have easy access to a named person or team with responsibility for coordinating all their care.

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2 Most of the data here are taken from Key facts and statistics, Asthma UK (online) accessed 16 February 2012. The data on hospital admissions are from Hospital Episode Statistics, NHS Information Centre, 2011.
3 Most of the data here are from Key Facts - Childhood Cancer, Cancer Research UK (online) accessed 16 February 2012. The data on survival rates are from Survival of Children, Teenagers and Young Adults with Cancer in England, National Cancer Intelligence Network, 2011.
4 Most of the data here are taken from Diabetes in the UK 2011/2012: Key statistics on diabetes, Diabetes UK, 2011. The data on hospital admissions are from Hospital Episode Statistics, NHS Information Centre, 2011.
5 The first data here are from Epilepsy facts, figures and terminology, Epilepsy Action (online) and For teenagers, Young Epilepsy (online) - both accessed 16 February 2012. The data on hospital admissions are from Hospital Episode Statistics, NHS Information Centre, 2011.