

# Long-term Conditions

## AYPH Research Update No. 9 - February 2012

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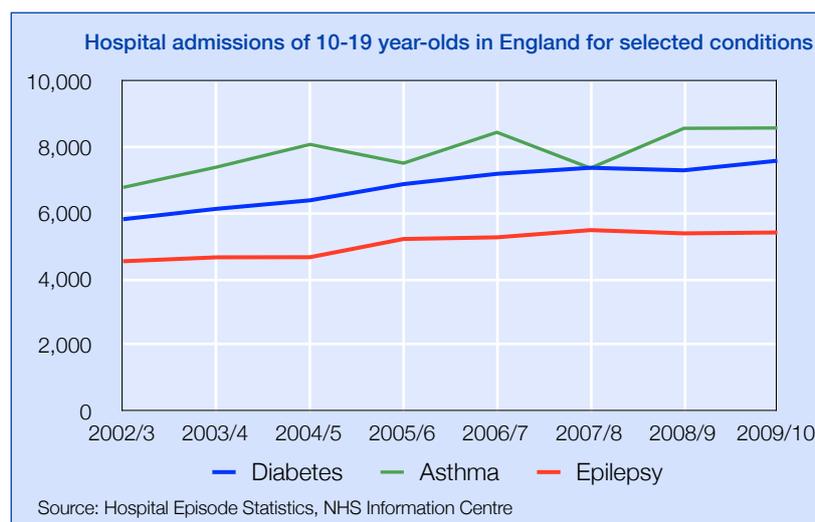
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## Introduction

This Update provides an overview of long-term conditions affecting adolescents. It complements our earlier summary on Disability 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 HBSC<sup>1</sup> 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<sup>2</sup>

- 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<sup>3</sup>

- 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<sup>4</sup>

- 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<sup>5</sup>

- 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.

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## 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.

Asthma UK believes that school inspections should measure the performance of schools in supporting and including children with long-term health conditions

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### 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](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 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.

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## Type of diabetes in England by age category

Age	Type 1		Type 2		Other types		Total	
	Number	Per cent	Number	Per cent	Number	Per cent	Number	Per cent
0-4	827	4.0	0	0.0	31	9.7	858	4.1
5-9	3,920	19.1	6	1.8	34	10.6	3,960	18.7
10-14	8,715	42.5	128	39.1	114	35.6	8,957	42.2
15-17	7,026	34.3	194	59.1	141	44.1	7,361	34.8
<b>Total</b>	<b>20,488</b>	<b>100</b>	<b>328</b>	<b>100</b>	<b>320</b>	<b>100</b>	<b>21,136</b>	<b>100</b>

- The overall diabetes prevalence rate for all children aged 0-17 in England was 209 per 100,000. However, there was substantial variation between regions with the prevalence rate ranging from 137 per 100,000 in the East Midlands, to 280 in the North East.

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## State of diabetes care in the UK 2009 - Diabetes UK, February 2010

<http://www.diabetes.org.uk/Professionals/Publications-reports-and-resources/Reports-statistics-and-case-studies/Reports/State-of-Diabetes-Care-in-the-UK-2009/>

Diabetes UK's report on progress towards delivering high-quality diabetes care draws on information gathered from a number of sources including a survey of over 16,000 of its members and data from the *National Diabetes Audit*. With huge increases in the numbers being diagnosed making diabetes one of the biggest health challenges facing us today, the report suggests there is still a long way to go before people with the condition can enjoy high-quality care across the whole UK.

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 Children's Charter presents key recommendations to ensure that children and young people with diabetes receive high-quality care, and calls for an end to discrimination in education, employment and public life

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).

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**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.

Key elements of effective self-care projects are providing a sense of community; promoting independence and confidence; developing knowledge and skills; and engaging young people

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.

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## 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

McDonagh J and Kaufman M, *Rheumatology*, (2009) 48:8 872-875

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. And, 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
- 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.

The 'You're Welcome' quality criteria serve as a helpful benchmark for developing young person-friendly health services

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**“What we want”:** chronically ill adolescents' preferences and priorities for improving health care  
van Staa A, Jedeloo S and van der Stege H, *Patient Preference and Adherence*, (2011): 5 291-305

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.

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### How children and young people construct and negotiate living with medical technology

Kirk S, *Social Science and Medicine*, (2010) 71: 1796-1803

With increasing numbers of children and young people needing the support of technology for their survival and well-being, this study involved in-depth interviews with 28 children and young people aged 8-19 living technology-assisted lives. The interviews and the techniques employed were tailored to the individual and sought to explore how medical technology was experienced and constructed by the young people and how it influenced their identity and social relationships with others.

Children across the age range who used different devices presented themselves as being determined to not allow the technology to define their lives or accept the barriers it created

This showed how children and young people see medical technology as a positive and negative presence, both improving and constraining their lives. It revealed how most were (selectively) open about their condition and device use and had incorporated the technology into their social identity and daily lives. However, this was an 'ongoing project' requiring continual work in response to changing social contexts and relationships. Driven by a desire for sameness, their identity work involves controlling information and self-presentation, to 'normalise' their bodies and lives as far as possible in order to fit in with their peers.

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### Contraception, Communicating and Counselling for Sexuality and Reproductive Health in Adolescents and Young Adults with Cystic Fibrosis

Tsang A, Moriarty C and Towns S (2010) *Paediatric Respiratory Reviews*, (2010) 11: 84-89

With significant improvements in the prognosis of cystic fibrosis (CF) and survival into the forties becoming more commonplace, the authors believe it has become increasingly important to consider issues of sexual and reproductive health in the management and care of young people with CF. While research indicates that adolescents and young adults with CF have similar hopes and expectations of establishing intimate relationships and contemplating parenthood, they may be significantly less well informed and have more concerns than their healthy peers.

For the adolescent, having CF is associated with being different to other young people, and may be resented, denied, hidden or ignored. This can result in varying degrees of non-adherence to treatment plans as teenagers' developmental priorities compete with the intensive treatment demands of their illness. The authors therefore emphasise the importance of considering how normal adolescent developmental, physical and cognitive changes interact with the challenges of living with a chronic, life-limiting illness. They discuss how coming to terms with emerging sexuality and intimacy can be especially difficult for adolescents with CF as they face uncertainty about the future and difficult decisions around disclosure within developing relationships. Long-term relationships, planning parenthood and coping with difficulties associated with CF are discussed, as is the crucial importance of education and counselling around contraceptive and reproductive issues to enable informed decision-making.

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### **Treatment non-adherence in teenage and young adult patients with cancer**

Kondryn C, Edmondson C, Hill J and Eden T, *Lancet Oncology*, (2011) 12: 100-108

Adherence to treatment can be a major issue for many people with long-term health conditions, especially for adolescents. However, little is known about adherence in teenagers and young adults with cancer, despite them being now required to take on far more responsibility for the administration of their treatment.

To increase awareness of the adherence challenges faced by these patients, the authors conducted a review of the limited evidence available. This indicates that a substantial proportion of teenagers and young adults do have difficulties, with four studies indicating that between 27% and 63% of teenage and young adult patients did not take their oral treatment as recommended. However, inconsistent findings across studies mean that the true extent of non-adherence for these patients is still unclear.

Factors that have been shown to affect treatment adherence in teenagers and young adults with cancer include patients' emotional functioning (depression and self-esteem), their health beliefs (perceived illness severity and vulnerability), and the family environment (parental support and parent-child concordance). The authors highlight multifactorial strategies that help to foster greater adherence, by targeting not just the patient but also the health professional, family and treatment regimen. They also address methodological issues and make suggestions for improving the design of much needed future studies.

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

Crowley R, Wolfe I, Lock K and McKee M, *Archives of Disease in Childhood*, (2011) 96: 548-553

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.

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### **Assessment of transition readiness skills and adherence in pediatric liver transplant recipients**

Fredericks E, Dore-Sites D, Well A, Magee J, Freed G, Shieck V and Lopez M, *Pediatric Transplantation*, (2010) December, 14(8): 944-953

As short-term survival rates among paediatric solid organ transplant recipients have improved, focus has shifted to longer-term outcomes. Long-term patient survival is limited by chronic rejection and graft loss,

with this being more common in adolescents. As increased risk for medical complications also arises with the transfer from paediatric to adult-centred transplant services, the authors identified a critical need to develop strategies to assess readiness for making this transition.

A sample of 71 paediatric liver transplant recipients with a mean age of 15.6 years and an average time since transplant of 9.4 years completed a clinically-developed transition readiness survey (TRS). This survey assesses perceived and demonstrated skills, as well as the allocation of responsibility for health management tasks. The results showed that nearly 30% of the participants were nonadherent with their immunosuppressant medications, and over 30% were nonadherent to scheduled clinic visits. There was also a significant association between age and non-adherence, with older adolescents and young adults exhibiting higher rates of nonadherence - with worrying implications for transition.

The timing of transfer should be individualised and based on the acquisition and mastery of self-management skills.

With respect to readiness for transition, perceived self-management skills also increased with age. However, greater chronological age was not associated with demonstrated self-management skills, including young peoples abilities to describe their medical regime or recognise critical health symptoms. While older adolescents and young adults perceived greater self-management, they were at higher risk for medication nonadherence. This leads the authors to re-emphasise the important role of parental monitoring and supervision to improve adherence to medication-related tasks. They also conclude that age alone should not determine readiness for transition to adult-focused health care.

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### Social networking for adolescents with severe haemophilia

Khair K, Holland M and Carrington S, *Haemophilia*, (2011): 1-7

While access to modern treatment allows adolescents with haemophilia to manage their condition at home, with improved treatment outcomes and quality of life, this also reduces peer support and the potential for experiential learning from older peers. The authors therefore sought to establish whether disease-specific social networking could benefit adolescents with haemophilia.

The first stage of the research involve focus group discussions with seven boys aged 9-17 with haemophilia. These explored how they balanced sport with treatment, reconciled their condition with being a teenager, and used online media and information. This informed the development of a detailed (paper and online) questionnaire which was sent to 150 adolescents aged 11-18 with severe haemophilia. It included questions about haemophilia knowledge, self-management skills and social network use. The findings were also discussed with six knowledgeable older boys recruited to help develop an expert patient programme.

The research established that four out of five respondents were frequent users of social network sites, mainly Facebook. Respondents frequently had only very limited contact with their peers but would like to meet other boys with haemophilia and are generally unafraid to discuss their condition with others. The authors go on to consider some of the benefits and potential drawbacks of online support groups. They also describe the [SixVibe website](#) which has now been developed for adolescents with haemophilia as part of the expert programme. In addition to educational content, the site includes games, a discussion forum and other features to facilitate the development of peer-to-peer transmission of disease management skills.

SixVibe includes a training scheme for users to become 'experts' in understanding and managing their haemophilia - effectively becoming advisers for younger patients using the site

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## Further references

- Adolescent onset of lupus results in more aggressive disease and worse outcomes...  
[Tucker L et al, \*Lupus\*, \(2008\) 17: 314-322](#)
- Assessment of knowledge in adolescents with inflammatory bowel disease using a novel transition tool  
[Bencimol et al, \*Inflammatory Bowel Diseases\*, \(2011\) May; 17\(5\): 1131-1137](#)
- Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with diabetes  
[Price et al, \*Child: care, health and development\*, \(2011\) 37\(6\): 852-860](#)
- Improving mental health transitions for young people with autism spectrum disorder  
[McConachie et al, \*Child: care, health and development\*, \(2011\) 37\(6\): 764-766](#)
- Minimizing infection and rejection death: clues acquired from 19 years of multi-institutional transplantation data  
[George et al, \*Journal of Lung and Heart Transplantation\*, \(2011\) Feb; 30\(2\): 151-157](#)
- Self-management education for cystic fibrosis  
[Savage et al, \*Cochrane Database of Systematic Reviews\*, \(2011\) Issue 7](#)
- Transition to adult services for children and young people with palliative care needs: a systematic review  
[Doug et al, \*Archives of Disease in Childhood\*, \(2011\) 96: 78-84](#)
- Unidentified Chronic Fatigue Syndrome/myalgic encephalomyelitis (CFS/ME) is a major cause of school absence...  
[Crawley et al, \*BMJ Open\*, \(2011\); 1](#)

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## Current initiatives

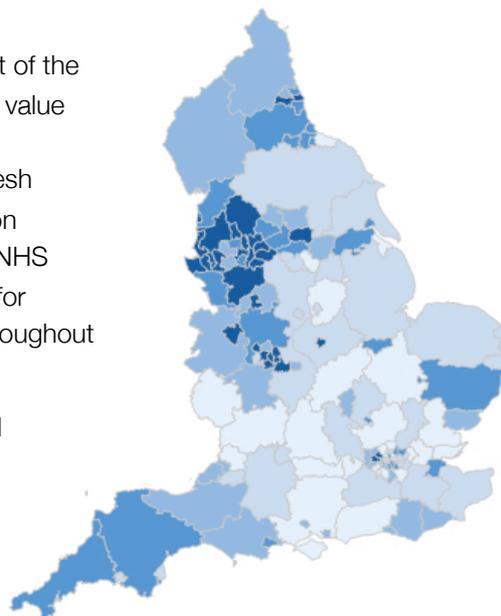
### NHS Atlas of Variation - November 2011

<http://www.rightcare.nhs.uk/index.php/nhs-atlas/>

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).



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

<http://www.rcpch.ac.uk/child-health/standards-care/clinical-audit-and-quality-improvement/epilepsy12-national-audit/epileps>

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.

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## **National Diabetes Paediatric Audit Report 2009-2010 - NHS Information Centre, 2011**

[http://www.ic.nhs.uk/webfiles/Services/NCASP/Diabetes/200910%20annual%20report%20documents/NHSIC\\_National\\_Diabetes\\_Paediatric\\_Audit\\_Report\\_2009\\_2010.pdf](http://www.ic.nhs.uk/webfiles/Services/NCASP/Diabetes/200910%20annual%20report%20documents/NHSIC_National_Diabetes_Paediatric_Audit_Report_2009_2010.pdf)

Among its key findings, this latest report of 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.

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## **Evidence into practice: evaluating a child-centred intervention for diabetes medicine management - The EPIC Project**

[Noyes J et al., \*BMC Pediatrics\*, \(2010\) 10: 70](#)

This protocol outlines a current research initiative to develop and evaluate an individually-tailored, age-appropriate diary and information pack to support decision-making and self-care relating to insulin management and blood glucose monitoring for young people aged 6-18 years with Type 1 diabetes.

Initial stages of the project have involved a systematic review of literature, policy, cost-effectiveness, best practice guidance and management plans. Together with the advice of an expert clinical group, this evidence has been used to inform the development of the diabetes diaries and information packs which were also designed in conjunction with children and young people, parents and healthcare professionals.

The diaries and packs have been designed for children and young people aged 6-10, 11-15 and 16-18. They have been developed to address the lack of high-quality, child-centred, effective health information available to support the development of self-care practices and expertise in children with acute and long-term conditions. The next phase of the study includes a randomised controlled trial to assess the effectiveness of these individually tailored resources compared with currently available standard practice. Data is being collected at baseline, three and six months, with HbA1c and other measurements being taken from test results and hand-held records when participants attend routine clinic appointments.

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### Transition

<http://research.ncl.ac.uk/transition>

Transition is a five-year research programme that aims to answer the question - how can health services contribute most effectively to facilitating successful transition of young people with complex health needs from childhood to adulthood? The programme commences in May, having been developed by Northumbria Healthcare NHS Foundation Trust and Newcastle University with funding from the National Institute of Health Research.



Despite the proliferation of guidance over the last 20 years, the [2010 Kennedy Review](#) and the [2011 Green Paper](#) on special needs and disability both stressed the importance of transition and the lack of progress made so far to achieving better health and social outcomes. The Transition programme therefore has three main objectives to:

1. work with young people with complex health needs to determine what successful transition means to them and what is important in their transitional care
2. identify the features of transitional care that are effective and efficient
3. determine how transitional care should be organised, provided and commissioned.

As well as involving young people with complex health needs in all aspects of the programme, the project will also include: a longitudinal study of 450 young people with autism, cerebral palsy and diabetes; an economic study to assess the relative importance of different components of success; and work with commissioners to determine what and how to commission.

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### 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. Its 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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## Policy framework

### Transition: moving on well - Department of Health, February 2008

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_083592](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083592)

This good practice guide on transition planning for young people with complex health needs built on earlier guidance which had been published just two years previously<sup>6</sup>. While that earlier advice recommended that the handover from paediatric services to adult services should be planned and managed as a process, this latest guidance concentrates on putting the young person at the centre of the transition planning process. This demands closer engagement with the young person to determine their aspirations and the support they are likely to need as they move out of child health services and assume increasing responsibility for their own care.

The overarching starting vision for *Transition: moving on well* is provided by Standard 4 of the Children's National Service Framework (Department of Health, 2004). In underlining the benefits of developing a personal health transition plan, the guidance recognises the need for transition services to support young people with a range of conditions, varying from those who will attain independence despite having a long-term condition, to others with a progressive, life-limiting disease.

The guidance advises that transition planning should be seen as an evolving process that is started in good time - one which increasingly encourages a young person to assume greater responsibility for their care, and parents to adapt to their changing needs. However, whatever model may be followed for health transition, the importance of effective multi-agency team working underpins all aspects of the guidance. It also highlights the particular value to young people and their families of having an identified key worker or health plan coordinator to support them through such a critical and complex process.

In making the transition to adulthood, young people should be supported to take responsibility for their own health and to make informed choices and decisions about their health and wellbeing both now and in the future

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### NICE clinical guidelines for children and young people with long-term conditions

Guidance produced by the National Institute for Health and Clinical Excellence (NICE) is designed to promote good health and prevent ill health. It is based on the best available evidence and sets standards for high quality healthcare used by the NHS, local authorities, voluntary organisations and others involved in delivering care or promoting wellbeing.

To date, NICE has published 145 clinical guidelines which make recommendations to the NHS on treating and caring for people with specific diseases and conditions. There are five guidelines within this set which relate explicitly to the treatment of long-term conditions affecting children and young people:

- [CG15](#) - Type 1 diabetes: diagnosis and management of Type 1 diabetes in children, young people and adults
- [CG28](#) - Depression in children and young people: Identification and management in primary, community and secondary care

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- [CG72](#) - Attention deficit hyperactivity disorder: Diagnosis and management of ADHD in children, young people and adults
- [CG128](#) - Autism: Recognition, referral and diagnosis of children and young people on the autism spectrum
- [CG137](#) - Epilepsy: The diagnosis and management of the epilepsies in adults and children in primary and secondary care.

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## Further resources

[A transition guide for all services](#) - Council for Disabled Children, Department of Health and Department for Children, Schools and Families, October 2007

Good practice guidance on the roles, responsibilities and duties for all service providers working with disabled young people (including those with complex health needs) through their transition to adulthood.

[Asthma at School \(School Policy Guide\)](#) - Asthma UK, 2006

Part of Asthma UK's resource packs for schools containing guidance for everyone involved in education to ensure that pupils with asthma are healthy, stay safe, achieve their potential and are able to make a positive contribution at school.

[Children's Charter for Diabetes](#) - Diabetes UK, May 2010

Charter setting out what Diabetes UK, children and young people, their families and healthcare professionals believe must happen to ensure high quality diabetes care, and to help achieve good physical and emotional wellbeing.

[Growing up with Cystic Fibrosis](#) - Cystic Fibrosis Trust, November 2001

A guide for young people aged 12-18 about what it is like to be a teenager with cystic fibrosis.

[HBSC England National Report](#) - University of Hertfordshire, October 2011

National report from the 2010 Health Behaviour in School-aged Children (HBSC) survey - a WHO cross-national study carried out to gain new insight into adolescent health behaviours, health and lifestyles in their social context.

['How to' guide: moving on to adult care services - young people with life-limiting and life-threatening conditions](#) - National Transition Support Team, 2009

Guidance outlining the key issues for young people with life-limiting and life-threatening conditions. It sets out what the main barriers are, an overview of good practice and a range of practical ideas and resources.

[Just Normal Young People: Supporting young people living with HIV in their transition to adulthood](#) - Children and Young People HIV Network/NCB, November 2011

Report detailing the experiences of young people, practitioners and parents/carers regarding the transition of young people living with HIV into adult life and adult-oriented services. Also includes policy and practice recommendations.

[National Framework for Children and Young People's Continuing Care](#) - Department of Health, March 2010

Sets out a framework for developing bespoke packages of care for children and young people with complex needs for continuing care that cannot be met by existing universal and specialist services alone.

[Needs-Based Palliative Care Commissioning for Children, Young People & their Families](#) - ACT, April 2011

Guide developed to help commissioners identify the types of services they should consider when commissioning provision for children and young people with life-limiting and/or life-threatening illnesses.

[Online Seizure Diary](#) - Young Epilepsy

This free online diary - 'All About Me' - helps young people to keep a record of their seizures and how the condition affects them. This information can also be printed off as a report and shared with medical professionals.

[Talking T1 - Learning About Type 1 Diabetes \(Resource Pack for Schools\)](#) - JDRF

Cross-curricular resources and toolkit for teachers, health professionals and parents which are designed to help schools support children with Type 1 diabetes in the classroom and to successfully integrate them in school life.

[Wish You Were Here, UK Report](#) - Asthma UK, 2008

Report highlighting significant disparities in asthma control and service provision across the UK which are reflected in significant variation between regions in emergency hospital admissions for children.

['You're Welcome': quality criteria for young people friendly health services](#) - Department of Health

Good practice guidance setting out principles to help commissioners and service providers improve the suitability of health services for young people - enhancing patient experience and increasing young people's opportunity to share in decisions about their health.

## Useful links

### Online resources for young people

- Association of Young People with ME - [www.ayme.org.uk](http://www.ayme.org.uk)
- Children and Young People HIV Network - [www.ncb.org.uk/hiv](http://www.ncb.org.uk/hiv)
- Kick-A (Asthma UK) - [www.kickasthma.org.uk](http://www.kickasthma.org.uk)
- My Life (Diabetes UK) - [www.diabetes.org.uk/Guide-to-diabetes/My-life/](http://www.diabetes.org.uk/Guide-to-diabetes/My-life/)
- T1 Teens (JDRF) - [www.jdrft1.org.uk](http://www.jdrft1.org.uk)
- YHeart (British Heart Foundation) - [www.yheart.net](http://www.yheart.net)
- You Got Nerves (Epilepsy Action) - <http://youngpeople.epilepsy.org.uk>
- Youthhealthtalk - [www.youthhealthtalk.org](http://www.youthhealthtalk.org)

### Other websites

- Arthritis Care - [www.arthritiscare.org.uk](http://www.arthritiscare.org.uk)
- Asthma UK - [www.asthma.org.uk](http://www.asthma.org.uk)
- British Heart Foundation - [www.bhf.org.uk](http://www.bhf.org.uk)
- Cancer Research UK - [www.cancerresearchuk.org](http://www.cancerresearchuk.org)
- CLIC Sargent - [www.clicsargent.org.uk/Home](http://www.clicsargent.org.uk/Home)
- Contact a Family - [www.cafamily.org.uk](http://www.cafamily.org.uk)
- Council for Disabled Children - [www.councilfordisabledchildren.org.uk](http://www.councilfordisabledchildren.org.uk)
- Cystic Fibrosis Task - [www.cftrust.org.uk](http://www.cftrust.org.uk)
- Diabetes UK - [www.diabetes.org.uk](http://www.diabetes.org.uk)
- JDRF - [www.jdrf.org.uk](http://www.jdrf.org.uk)
- Kidney Research UK - [www.kidneyresearchuk.org](http://www.kidneyresearchuk.org)
- Muscular Dystrophy Campaign - [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)
- National Cancer Intelligence Network - [www.ncin.org.uk](http://www.ncin.org.uk)
- On Your Own Feet - <http://www.oxygenbenen.nu/en/general/>
- Sickle Cell Society - [www.sicklecellsociety.org](http://www.sicklecellsociety.org)
- Teenagers and Young Adults with Cancer - [www.tyac.org.uk](http://www.tyac.org.uk)
- Teenage Cancer Trust - [www.teenagecancertrust.org](http://www.teenagecancertrust.org)
- Medical Conditions at School - [www.medicalconditionsatschool.org.uk](http://www.medicalconditionsatschool.org.uk)
- Together for Short Lives - [www.childhospice.org.uk/home.aspx](http://www.childhospice.org.uk/home.aspx)
- Transition Information Network - [www.transitioninfonetwork.org.uk](http://www.transitioninfonetwork.org.uk)
- Young Epilepsy - [www.youngpilepsy.org.uk](http://www.youngpilepsy.org.uk)

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<sup>1</sup> *Health Behaviour in School-aged Children (HBSC)* - England National Report, University of Hertfordshire, 2011.

<sup>2</sup> 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.

<sup>3</sup> 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.

<sup>4</sup> 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.

<sup>5</sup> 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.

<sup>6</sup> *Transition: getting it right for young people*, Department of Health, 2006.