

## Appendix 2: websites and policy documents

### POLICY DOCUMENTS (reference lists handsearched)

NICE guidance <https://www.nice.org.uk/guidance>

The search of NICE guidance took place at a time when the website was undergoing changes. Were we to re-run searches, we would use the population filter at <https://www.nice.org.uk/Guidance/Population-groups/Children-and-young-people>. Our wide searches also captured adult guidance but we have deleted from this version those where references to children were not substantial.

Also relevant for future searches is Domain 4 of NICE quality standards on the experience of care <https://www.nice.org.uk/Media/Default/Standards-and-indicators/Quality-standards/NHS-OF-to-QS-mapping.pdf>

- NICE (2014) *The MAGEC system for spinal lengthening in children with scoliosis: guidance* <https://www.nice.org.uk/guidance/MTG18>
- NICE (2013) *Hepatitis B (chronic) Diagnosis and management of chronic hepatitis B in children, young people and adults* <http://www.nice.org.uk/guidance/CG165>
- NICE (2013) *Ulcerative colitis Management in adults, children and young people* <http://www.nice.org.uk/guidance/CG166>
- NICE (2012) *Crohn's Disease: management in adults, children and young people* <http://www.nice.org.uk/guidance/cg152>
- NICE (2012) *Psoriasis assessment and management of psoriasis in adults young people and children* <http://www.nice.org.uk/guidance/cg153>
- NICE (2012) *Sickle cell acute painful episode Management of an acute painful sickle cell episode in hospital* <http://www.nice.org.uk/guidance/cg143>
- NICE (2012) *The Epilepsies The diagnosis and management of the epilepsies in adults and children in primary and secondary care* <http://www.nice.org.uk/guidance/cg137>
- NICE (2012) *Spasticity in children and young people with non-progressive brain disorders: management of spasticity and co-existing motor disorders and their early musculoskeletal complications* <http://www.nice.org.uk/guidance/cg145>
- NICE (2011) *Food allergy in children and young people: Diagnosis and assessment of food allergy in children and young people in primary care and community settings* <http://www.nice.org.uk/guidance/cg116/resources/cg116-food-allergy-in-children-and-young-people-full-guideline3>
- NICE (2011) *Tuberculosis* <http://www.nice.org.uk/guidance/CG117/chapter/1-Guidance>
- NICE (2010) *Human growth hormone (somatropin) for the treatment of growth failure in children: guidance* <http://www.nice.org.uk/guidance/ta188>
- NICE (2010) *Obesity: full guideline, section 5a - management of obesity in clinical settings (children): evidence statements and reviews* <https://www.nice.org.uk/guidance/cq43/resources/cq43-obesity-full-guideline-section-5a-management-of-obesity-in-clinical-settings-children-evidence-statements-and-reviews-ms-word-format>
- NICE (2009) *Recognition and Assessment of Coeliac Disease and the Care of Children and Adults* <http://www.nice.org.uk/guidance/cq86>
- NICE (2007) *Atopic eczema in children: full guideline* <http://www.nice.org.uk/guidance/CG57>
- NICE (2007) *Chronic fatigue syndrome /Myalgic encephalomyelitis in adults and children* <http://www.nice.org.uk/guidance/CG53> also incorporating Royal College of Paediatrics & Child Health. Evidence Based Guideline for the Management of CFS/ME (Chronic Fatigue Syndrome/Myalgic Encephalopathy) in Children and Young People
- NICE (2005) *Improving Outcomes in Children and Young People with Cancer* <http://www.nice.org.uk/guidance/csgcyp>
- NICE (2004) *Vagus nerve stimulation for refractory epilepsy in children Identifying and managing tuberculosis among hard-to-reach groups* <http://www.nice.org.uk/guidance/ipg50>

## National Service Frameworks

- Department of Health (2010). *National Service Framework for Children, Young People and Maternity Services - Type 1 diabetes in childhood and adolescence*
- Department of Health (2005). *National Service Framework for Long term Conditions*
- Department of Health (2004). *National Service Framework for Children, Young People and Maternity Services: Asthma*;

## Department of Health

- Department of Health (2004) *Wanless Report: Securing good health for the whole population*
- Department of Health (2006) *Transition: getting it right for young people: Improving the transition of young people with long term conditions from children's to adult health services*
- Department of Health (2007) *Making every young person with diabetes matter*
- Department of Health (2008). *Better Care: Better Lives. Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions*
- Department of Health (2009). *Healthy lives, brighter futures: The strategy for children and young people's health*
- Department of Health (2010). *Getting it right for children and young people- overcoming cultural barriers in the NHS so as to meet their needs* (Kennedy Review)
- Department of Health (2012). *Our Children Deserve Better: Prevention Pays*
- Department of Health (2013). *Children and young people's health outcomes forum – report of the long-term conditions, disability and palliative care subgroup*

## Other

- Department for Education and Skills and HM Treasury (2007). *Aiming high for disabled children: better support for families*
- British Association of Dermatologists (2012). *Working Party report on minimum standards for paediatric services, 2012*
- BMA (2013). *Growing up in the UK: ensuring a healthy future*
- Marmot Review (2010) *Child Health Task Group Report*
- Royal College of Paediatrics and Child Health (2009). *Growing up with diabetes: children and young people with diabetes in England*
- CQC (2014). *Teenagers with complex health needs lack support as they approach adulthood*
- Royal College of Paediatrics and Child Health (2009). *Modelling the future III Safe and sustainable integrated health services for infants, children and young people*
- King's Fund (2013). *Delivering better services for people with long-term conditions- Building the house of care*
- King's Fund (2014). *Improving care for long term conditions*

## WEBSITES

National Children's Bureau [www.ncb.org.uk](http://www.ncb.org.uk) searched using terms 'chronic', long-term' and 'diabetes'; hand-searched publications/other resources pages; from this, we retrieved one study which met our inclusion criteria (Kirk et al 2012)

The Children's HIV organisation [www.chiva.org.uk](http://www.chiva.org.uk) handsearched resource page

The Transition Information Network <http://www.transitioninforonetwork.org.uk/> hand-searched resources and publication pages

NICE Evidence <https://www.evidence.nhs.uk/> was searched using terms: 'children' AND 'chronic' AND 'experience' AND 'qualitative' AND 'care'. The *first ten* hits were ordered in terms of relevance and titles read, and yielded one study which met our inclusion criteria (Williams et al 2011).

GOOGLE UK <https://www.google.co.uk/> search using search terms: 'Sickle Cell', 'Thalassaemia', 'Cystic Fibrosis', 'Duchenne' (conditions not covered above) limited search to first two pages of each condition only.