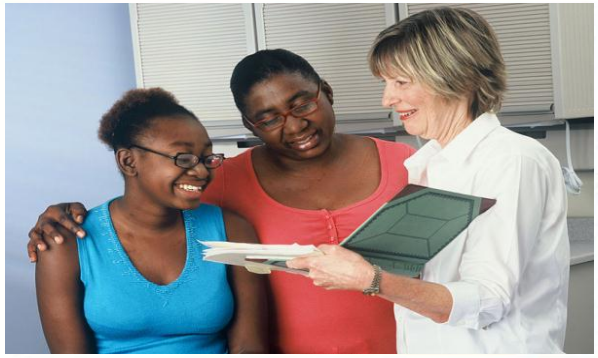
NHS England

Strategic Clinical Networks and Senate
Yorkshire and the Humber

Children's & Maternity

Strategic Clinical Network

Yorkshire & the Humber



Transition

Key Themes & Principles

July 2014

THE NHS CONSTITUTION
the NHS belongs to us all

Documents - Transition

Date	Author	Title	Description	Link
2014	CQC	From the Pond into the Sea	The findings from the CQC recent review show that young people with complex health needs do not always receive the necessary care and support when they move on to adult care services.	http://www.cqc.org.uk/content/teenagers-disabilities-and-long-term-health-needs-lack-appropriate-support-they-approach
2014	NHS England	Annex 1.Paediatric Medicine- Specialised Generic Children's Services Specification Insert	This is an appendix to all the individual specialised services specifications	Not available on line
2014	NHS England (Still in Draft)	Generic Specification for Transition	Specification insert; Generic Specification for Transition. Generic specification to support young people in the transition process from paediatric to adult specialist health care services	Not available on line
2014	NICE	SCOPE ONLY - Draft Guidance	The draft scope is out for consultation with stakeholders. The scope defines what aspects of care the guideline will cover and to whom it will apply. The guidance is due to be developed by 2016.	http://www.nice.org.uk/Guidance/InDevelopment/GID-TRANSITIONCHILDRENSADULTSSERVICES
2014	University Hospital Southampton	Read, Steady, Go	Ready Steady Go transition programme for parents and children over 11years old with a long-term medical condition. A programme to help CHYP get ready and feel confident to move to adult services around 18 years of age.	http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx

Documents - Transition

Date	Author	Title	Description	Link
2013	RCN	Lost in Transition	Guidance from the Royal College of Nursing about managing young people's transition to adult services.	http://www.rcn.org.uk/__data/assets/pdf_file/0010/157879/003227_WEB.pdf
2011	DH	You're Welcome. Quality Criteria for Young Persons Friendly Services	'You're Welcome', sets out principles to help commissioners and service providers to improve the suitability of NHS and non-NHS health services for young people.	https://www.gov.uk/government/publications/quality-criteria-for-young-people-friendly-health-services
2010	Professor Sir Ian Kennedy	Getting it right for children and young people. Overcoming cultural barriers in the NHS so as to meet their needs	The review concentrates on understanding the role of culture in the NHS. It focuses on those areas where there are cultural barriers to change and improvement. It examines the NHS's position in a wider system of care and support, so as to understand and improve the NHS's provision of services to children and young people.	https://www.gov.uk/government/publications/getting-it-right-for-children-and-young-people-overcoming-cultural-barriers-in-the-nhs-so-as-to-meet-their-needs
2008	DH	Moving on Well	A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability.	http://www.bacdis.org.uk/policy/documents/transition_moving-on-well.pdf

Documents - Transition				
Date	**Author**	**Title**	**Description**	**Link**
2008	Royal College of Physicians of Edinburgh Transition Steering Group.	Think transition developing the essential link between paediatric and adult care	This guidance was designed to raise awareness of the important issues facing young people as they move from paediatric to adult care, and to provide all concerned with practical support to improve their experiences	http://www.cen.scot.nhs.uk/files/16o-think-transition-edinburgh.pdf
2006	DH	Transition: getting it right for young people - Improving the transition of young people with long term conditions from children's to adult health services	This good practice guide aims to bring together current understanding and knowledge on the subject of transition between paediatrics and adult services. Wherever possible it relies on published evidence as well as opinion and expert knowledge derived from the USA, Canada and Australia as well as the UK. Inevitably there is a particular focus on healthcare but the importance of a broad multidisciplinary approach to transition is emphasised throughout	https://www.bspar.org.uk/DocStore/FileLibrary/PDFs/Transition-%20getting%20it%20right%20for%20young%20people%20-%2023rd%20March%202006.pdf
2003	DH	National Service Framework hospital standards	This document sets a standard for the care of children and young people when they are in hospital.	http://www.nhs.uk/nhsengland/aboutnhsservices/documents/nsf%20children%20in%20hospitlaldh_4067251%5B1%5D.pdf

Documents: Specific diseases/conditions: - DIABETES

Date	Author	Title	Description	Link
2014	Peter H Winocour	Care of adolescents and young adults with diabetes – much more than transitional care: a personal view	Journal Article	http://www.ncbi.nlm.nih.gov/pubmed/24889572
2013	Kime, N., Bagnall, A-M. and Day, R.	Systematic review of transition models for young people with long-term conditions: A report for NHS Diabetes London; NHS Diabetes.	With this in mind NHS Diabetes commissioned Leeds Metropolitan University to undertake a systematic review, the aim being to provide an overall picture of the current situation in relation to transition services for young people with LTCs.	https://www.diabetes.org.uk/Documents/nhs-diabetes/paediatrics/systematic-review-transition-models-young-people-longterm-conditions.pdf
2012	NHS Diabetes	Diabetes – Quality Standards for Transition	To provide a short checklist of diabetes specific information needed by a service to ensure they are offering a good quality transition process	http://www.diabetes.org.uk/Documents/About%20Us/What%20we%20say/Quality%20standards%20for%20transition.pdf
2012	NHS Diabetes	Diabetes transition	Assessment of current best practice and development of a future work programme to improve the transition processes for young people with diabetes	http://www.diabetes.org.uk/Documents/nhsdiabetes/paediatrics/diabetes-transition-report.pdf'

Further Reading

Date	Author	Title	Description	Link
2014	Monitor	Enabling integrated care in the NHS	Information, guidance and links to further documents to support commissioners and providers around integrated care.	https://www.gov.uk/enabling-integrated-care-in-the-nhs
2013	Public Health England	Health and care integration: making the case from a public health perspective	Explains the role of public health in supporting local areas to maintain a focus on integration that keeps people well	Health and care integration: making the case from a public health perspective
2013	DOH - National Collaboration for Integrated Care and Support	Integrated care and support: our shared commitment	This framework document on integration, signed by 12 national partners, sets out how local areas can use existing structures such as Health and Wellbeing Boards to bring together local authorities, the NHS, care and support providers, education, housing services, public health and others to make further steps towards integration.	https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/287815/DEFINITIVE_FINAL_VERSION_Integrated_Care_and_Support_-_Our_Shared_Commitment_2013-05-13.pdf
2013	Monitor	Supporting integrated care through regulation	(requires Knowledge Hub registration) - advice on how to achieve integration successfully within your local health and care economies	Supporting integrated care through regulation - an introduction to how and why Monitor is actively working to enable the delivery of integrated care
2012	Monitor	Enablers and Barriers to Integrated Care and Implications for Monitor.	This report gives an overview of what integrated care is and what can block or enable it, and makes recommendations for how Monitor can carry out its duty to enable integrated care	Enablers and barriers to integrated care and implications for Monitor

Further Reading

Date	Author	Title	Description	Link
2011	Crowley R et al.	'Improving the Transition between paediatric and adult healthcare – A systematic review', Arch Dis Child	A systematic literature review in July 2010 of studies which consistently evaluated health outcomes following transition programmes, either by comparison with a control group or by measurement pre-intervention and post-intervention	http://www.ncbi.nlm.nih.gov/pubmed/21388969
2010	Royal College of Paediatrics and Child Health	Not just a phase. A Guide to the Participation of Children and Young People in Health Services	The publication provides information to ensure the safe, meaningful and ethical participation of children and young people within the delivery of quality child health services. It also practically demonstrates how we can contribute towards creating a culture of participation. The publication has been developed and published by the RCPCH and the Young People's Health Special Interest Group.	http://www.rcpch.ac.uk/what-we-do/children-and-youth-participation/not-just-phase-guide-participation-children-and-young-pe

Commissioning (including Funding/Budget)	
CQC Report	• Commissioners must listen to and learn from young people and their families. • Review of how these services are commissioned, commissioners must listen more effectively to young people and their families and deliver better, more effective, joined-up services • Respite and short break facilities available to meet their needs and those of their families. • Services commissioned in adult's service must be appropriate for Young People during transition. • Effective health contribution to strategic planning for transition service. • Agreement over funding for equipment, respite and other requirements during transition needs to be clear. • Funding arrangements and changes must be clear and explicit for CHYP, parents and carers during the transition process and changes in funding in the move to adult services. • Continuing health care assessments to allocate funding need to be carried out by a professional that has good knowledge of the young person and their situation.
Annex 1.Paediatric Medicine-Specialised Generic Children's Services Specification Insert	• Services are commissioned and delivered according to national or locally agreed best practise guidelines and standards. • There is evidence of critical review of current services, considering reconfiguration, integration and networked care. • Commissioners ensure providers have critically appraised and adapted service delivery models to transform care across the health care system.
Lost in Transition - RCN	• Services need to be viewed in a new light to ensure they work most effectively for young people.
Transition: getting it right for young people - Improving the transition of young people with long term conditions from children's to adult health services (DH 2006)	• Commissioners need to be well informed about transition. • Where NHS commissioner's co-commission services with their local authority partners and purchase packages of care for young people with complex needs, this should help to ensure that future service and support requirements are already agreed by the time the young person is ready for transition. • Commissioning and funding arrangements - should stress flexibility about the age of transition and the way the young person is managed after transition to adult services.

Moving on Well (DH 2008)	• Services that reflect the need for a comprehensive transition health team, with specific roles as well as generic competencies. • Clarification of unmet needs and informing commissioners; • Health representation on local transition strategy groups. • Service redesign needs to be underpinned by effective commissioning of transition health services. Central to this is joint planning based on a shared understanding of local needs. Health professionals, managers and commissioners need to work together to design, commission and implement accessible and effective services to assure young people and families of the provision of coordinated, uninterrupted healthcare. • A joint planning and funding process within the PCT (now CCGs)/primary care/local authority for multiple, ongoing needs. • Specialist commissioning for needs, such as palliative care or rarer conditions, where evidence demonstrates the benefits of regional partnerships or more centralised tertiary services in conjunction with managed health networks. • A 'whole-systems' approach, identifying and involving key players from the start, including adult health services, primary care and other agencies. • Collaborative working between commissioners and providers responsible for commissioning children's and adult services in PCTs, acute health trusts and other agencies. • Appointment of a health transition lead (a local 'transition champion') to promote and coordinate transition developments across care groups and between children's and adult services, and identify this responsibility in their job description and/or job plan. • Agreed categories of need, based on collected data, taking account of user views, for example through young people/parent forums and professional consultation. • Reviewing existing provision against the needs of young people. • Developing a pathway especially for young adults in partnership with clinicians in child and adult health services across the range of specialties and services. • Consulting with key partners – local authority, schools, the learning and skills council, lead council members and non-statutory organisations – making use of joint commissioning, pooled budgets or direct payments to fund services and increase user choice. • Improving accuracy of tariffs for existing and planned services. • Monitoring and reviewing services and outcomes on a regular basis. • Plan and commission service developments in light of identified needs, the evidence base, good practice and professional guidance. • The mechanism for collating information about outcomes/service requirements and reporting to commissioners needs to be clearly specified. This should lead to more focused commissioning (rather than block contracts). • Flexible funding and contractual arrangements (across paediatric/young adult services) to meet individual needs. • Services built around a professional lead role; commissioning on these lines can develop transition services with working protocols for both specific assessment of individuals and a training component to support other staff.

Getting it right for children and young people. Overcoming cultural barriers in the NHS so as to meet their needs - A review by Professor Sir Ian Kennedy (September 2010).	• Currently, there is a division of funding between services for adults and those for young people. While it may be bureaucratically convenient to draw a clear line between the two streams of funding, it makes no sense at all to the young person. Future arrangements must ensure that there is a greater flexibility, allowing for greater continuity of care even into early adulthood. • Funding for the health and healthcare of children and young people and for 'transition' to adulthood must be identified, separated from the funding dedicated to the care of adults, and transferred to the responsible government department for further distribution to organisations at local level. • The commissioning of all services, including those of the NHS, called for by the Local Partnership's agenda and plan must be carried out in such a way as to ensure that the services are complementary and efficiently delivered. • Those commissioning health services for children and young people should use their influence through commissioning, contracting and funding to require providers to design services around the needs of children or young people, establish a single portal of access, ensure that care is delivered in line with the normal pathway of care, and require the collection, analysis and dissemination of information. • Arrangements must be agreed, regarding funding and other matters, to address the changing needs of children and young people as they mature, including greater continuity of care into adulthood. Ensuring a smooth transition between children's and adults' services should be a priority for local commissioners.

Integration & Multi Agency Working (including Local Authority, Social Care and Mental Health Services)	
Generic Specification for Transition	• Quality Standard 3 - The paediatric and adult services will work together with local primary and secondary care and other multi-agency services to enable holistic and integrated person centred care planning and delivery. Working together processes are built into the transition policy at service and provider level. • The interdependencies with providers of primary and secondary health care services, education and social care, with particular reference to child, adolescent and adult mental health and 0 – 25 SEND services are noted. Any policy or pathway covering transition in the specialist health services.
CQC Report	• The provision of healthcare and services to meet other needs, including social care, life skills, and educational needs must be coordinated and the lead taken by professionals not parents and carers. • Services should be developed with the involvement of CHYP, parents and Carers. • Continuing care package criteria and transitions planning should be of a high quality and consistent for all CHYP (often this is better for CHYP who are attending special schools or have ongoing health needs.) • A system-wide change is needed to achieve a joined-up approach • It is the local authority and educational establishments who are the key drivers in the preparation and planning of transition. This may or may not include the health arrangements
NICE Draft Guidance	• The guidance will cover all settings in which a transition from children's to adult health or social care services takes place including primary, community, and residential, secondary care and secure settings (including young offender institutions). This includes transition from specialist care to general practice, including if the GP is the care coordinator. • Joint working between children's and adult services (health and social care, and with education services where education is leading the transition planning). • What are the contributions and impact of the voluntary and community sectors in supporting transition?
Lost in Transition - RCN	• Local services must work together, along with the young people and their families, to plan the transition. • Local services must work together with mental health services where necessary, including child and adolescent mental health services, adult mental health services and emergency inpatient services. • In planning to meet an individual's needs, NHS and social care providers should not overlook the services available locally from the voluntary sector.

Integration & Multi Agency Working (including Local Authority, Social Care and Mental Health Services)	
National Service Framework hospital standards (DH, 2003)	• Services need to work together to help children to reach their full potential. • Primary health care and social care involvement, for continuity and to meet broader health and social care needs.
Transition: getting it right for young people - Improving the transition of young people with long term conditions from children's to adult health services (DH 2006)	• Successful transition planning and programmes are crucially dependent on collaboration between children's and adult services. • Establish a shared philosophy between adult and paediatric care. • Share information between services; ensure multi agency working, co-ordination and accountability across different organisations within the public sector and voluntary organisations.
Moving on Well (DH 2008)	• The need for a clear inter-agency planning structure which is based on good communication, education and training of staff, has agreed protocols that take account of national standards and evaluates outcomes of local planning to improve experiences of transition for these young people. • Work closely with other agencies to ensure that the health plan is shared, when appropriate, and incorporated into a young person's broader transition plan (through the statutory review process for those with SEN statements but also for other young people). • The importance of multi-agency working underpins all sections of this guidance. Within the multi-agency team, a key worker and key worker designate needs to be identified for each individual young person. • The overall transition plan requires multidisciplinary and multi-agency input. • Throughout the transition process, all agencies have a responsibility to work together. • A multi-agency model. • Multi-agency transition teams which include core health professionals as a minimum. • Health professionals working jointly with the local authority to develop individual care packages for young people with health needs who meet continuing care criteria.

Integration & Multi Agency Working (including Local Authority, Social Care and Mental Health Services)	
Think transition Developing the essential link between paediatric and adult care (Royal College of Physicians of Edinburgh Transition Steering Group, 2008).	• Many commentators advocate a multi-professional approach to intervention. This may involve collaboration between doctors, school health service professionals, young offenders' teams, social workers, youth workers and specialist treatment centres. • Liaison between health and education services is also valuable for adolescent sexual health and relationship issues. Multi-professional collaboration may help to ensure that adolescent health services are provided seamlessly and that adolescents do not suffer harm during the transition between children's and adult services. • Transition services must be multidisciplinary and multi-agency, involving the specialty team(s) at the paediatric, district or rural general hospital, the adult providers and general practice, education, social services and voluntary agencies. There is no one model that fits all.
Getting it right for children and young people. Overcoming cultural barriers in the NHS so as to meet their needs - A review by Professor Sir Ian Kennedy (September 2010).	• It is essential that local organisations come together to ensure that the young person can enjoy a continuity of care that ignores birthdays and concentrates on needs. • There should be a dedicated Local Partnership in every Local Authority or similar area which is responsible for the planning and delivery of children and young people's health and healthcare at the local level and for integrating these services into all of the services provided. • There should be local networks through which services can share information electronically and protocols should be agreed by the networks to provide for this.
You're Welcome. Quality Criteria for Young Persons Friendly Services (DH 2011)	• Joined-up working - This theme addresses some of the ways to ensure effective joined up delivery. • Where possible, other relevant services for young people are co-located within the service. Where this is not the case, the service provides information about other local services for young people. All staff are familiar with local service provision and arrangements for referral. • Information about the service is provided to other relevant organisations and to key professionals working with young people.

Transition Process and Transition Plan

Generic Specification for Transition	**Transition Process** • Between the ages of 13 – 25 as a minimum expectation for generic application. • Transition process that is based on developmentally appropriate care planning. • All young people have the name of the health care professional responsible for their transition co-ordination recorded in their notes / EPR. • All young people and their parent's/ carers can identify the person in their team responsible for co-ordinating their health transition care planning and know how to contact them. • Delivered by processes, systems and environments that promote safety, quality, and effectiveness and are young people friendly. • Quality standard 4 - All young people identified in paediatric services are likely to need the continuing assessment, review and intervention of adult health services as a result of a long term condition / complex health needs has a person centred plan which covers: ➢ Developmentally attuned preparation for increased autonomy and self-management. ➢ Co-ordinated and supported transfer planning in partnership with young person and their support system led by a named health professional. ➢ Developmentally attuned integration into adult receiving services with proactive support to maintain engagement with services. **Transition Plan** • Documented in the young person's medical records and reviewed at key points in the transition pathway (preparation, supported transfer and integration in the adult service). • Care plans include transition support. • All young people identified as requiring transition preparation, supported transfers and continuity of transition focused care in adult services have assessments, action plans, reviews and transfer reports documented in their notes / electronic records across tertiary, secondary and primary.

Transition Process and Transition Plan	
CQC Report	**Transition Process** • A key accountable (lead professionals) individual responsible for supporting their move to adult health services. • Clear and transparent process, for CHYP, Parents/Carers and Professionals. • Approaches need to be flexible as what works for one 14-year-old may not work for another because of developmental maturity and their resulting needs. • The system needs to be less fragmented (health & Social Care) and CHYP, Parents and Carers need to tell their story once (or as little as possible). • Need to agree a consistent age when preparation for transition begins e.g. 12, 14, and 16? • CHYP must have positive experiences of transferring to adult services. • Robust monitoring and evaluation (Quality Assurance) must be in place to measure outcomes of the transition process. • Services must have good communication with young people, their parents and each other. **Transition Plan** • All CHYP must have a documented transition plan that includes their health needs. • Transition planning must be timely and not delayed. • A communication or 'health passport' to ensure relevant professionals have access to essential information about the young person. • Health assessments must be up to date and carried out in a timely manner.
NICE Draft Guidance	**Transition Process** • Cover all young people in transition (aged up to 25). • Transition in this guideline is defined as a purposeful and planned transition from children's to adult services. • Interventions to support effective transition (such as the services or support provided by transition workers, peer support groups and transition clinics) • What factors contribute to successful and unsuccessful transitions, as identified by young people, their families and carers, • Transition readiness (as measured by relevant scales, for example, the Rotterdam Transition Profile). • Continuity of care

Transition Process and Transition Plan	
NICE Draft Guidance	**Transition Plan** • Care planning, coordination and assessment. • Barriers to, and facilitators of, good practice in transition planning (a key issue because of the current disconnection between existing policy guidance and practice).
Lost in Transition - RCN	**Transition Process** • Services should designate a key worker or lead professional to work with a young person, their family and relevant services to plan the transition. • Transitional points are set as recommended in the English and Welsh National Service Frameworks, and some flexibility is built in to meet individual needs. • Transition should appear as seamless as possible to the young person • If possible, the young person should have the opportunity to visit the clinic in advance or meet the team who will take on their care. They should be given time and support to adjust to the transition, and the opportunity to say goodbye to staff and friends connected to the children's service before they leave. • Receiving team or staff member is identified in adult services to welcome and support young people entering their care. • Care is handed over in a planned and collaborative way, through meetings between at least one key professional from both services and the young person (and their parents/carers if appropriate). **Transition Plan** • A comprehensive written summary of the CAMHS notes is available to the receiving service, with appropriate consent for the receiving service to help provide an overview of past mental health issues.
National Service Framework hospital standards (DH, 2003).	**Transition Process** • A co-ordinated transfer process. A named co-ordinator should be identified, who will be responsible for arranging a personal introduction and a visit to adult services. This may include co-ordination across health, social care, further education and employment. • It may be useful to set a target age; there is no 'right' time for transition. A flexible approach is called for that takes developmental readiness into account, and links to other social transitions such as leaving school.

Transition Process and Transition Plan

National Service Framework hospital standards (DH, 2003).	**Transition Plan** • All young people with on-going health needs should have a plan developed with them for the transition of their care to adult services. • Administrative support, to ensure smooth transfer of medical, social care and other relevant records, provision of summaries including a handheld summary for the patient's own use, and efficiently organised appointments.
Transition: getting it right for young people - Improving the transition of young people with long term conditions from children's to adult health services (DH 2006)	**Transition Process** • Transition should be viewed as a process and not as a single event, plan a co-ordinated transfer process and Identify a co-ordinator • Implementing improved transition involves: recognition of the importance of the process; adequate consultation with professionals and users; flexibility in the timing of transition; a period of preparation for the young person and family; information transfer; monitoring of attendance until the young person is established in the appropriate adult oriented service. • Active management of transition - consider the timing; plan early and prepare for leaving children's services and arriving at the adult service. • Stress the importance of a trusted adult who can challenge and support them, act as an advocate and help them to develop self-advocacy skills. • Address loss of continuity of care at transition; ensure new relationships are established. • There is no one "right" time or age for transition. Rigid age limits defining children's and adult services are undesirable and there is no fundamental reason for them other than financial convenience. • Timing must depend on the developmental readiness and health status of the individual adolescent as well as the capabilities of the adult providers. • "Person centred" approach to transition planning which is based on the young person's aspirations and not on what providers find it convenient to offer. **Transition Plan** • Consider Information transfer, giving copies of key letters and summaries to the young person to keep in a Personal Health Record, Health Passports and ensuring that GPs are kept fully informed are helpful strategies.

Transition Process and Transition Plan

Moving on Well (DH 2008)	**Transition Process** • The process of transition should start while the child is being cared for by children's services and may, subject to the needs of the young person; continue for a number of years after the transfer to adult services. • Place the young person's needs and aspirations at the centre of the transition process. • Starting by 13 years old at the latest. • One main person who can help guide them through the complex transition process. With the agreement of the young person, the transition key worker (key worker) and/or professional in the child health team who has most ongoing involvement with the young person and family and/or the key worker designate in adult services is best placed to fulfil this coordination role and work with the young person. • A focus on person-centred planning. • Clear identification of the key worker and key worker designate. • Transition teams with core professionals who deliver a comprehensive service. **Transition Plan** • The health plan needs to be developed by the young person, supported by the most relevant health professional/transition key worker or other relevant multidisciplinary team member who can review it regularly with them. • The health plan should be initiated at the start of the transition planning process. In line with transition planning in schools. • A health plan comprises a self-assessment by the young person to identify their day-to-day needs and, in discussion with health professionals, an action plan to meet these needs in preparation for moving into adult healthcare provision. (The Document continues to provide further detail of what may be included in a health plan and the benefits.) • Assessment of immediate medical needs and potential future needs, including risk assessment. • Flexible, timely response: early intervention and prevention through individual health plans, avoiding hospital admission, where possible.

Transition Process and Transition Plan

Think transition Developing the essential link between paediatric and adult care (Royal College of Physicians of Edinburgh Transition Steering Group, 2008).	**Transition Process** • In healthcare terms, transition is "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented healthcare systems". • One positive change clinicians can make during transition is to provide opportunities for young people to see them independently of their parents. • Emerging evidence supports the generally accepted notions that the process of transition should begin as early as possible, generally by secondary school age, and in the later stages involve opportunities to meet and interact with adult clinicians. • However, there is no "right" time or age for the subsequent transfer to take place. Chronological age should not be the only criterion for deciding when to transfer a patient; the transfer must also take place at a developmentally appropriate time. • Age of transition can differ depending on the different disease-specific and psychosocial needs of young people. • Importantly, when deciding on transfer timing, account should be taken of the many other transitions and significant events taking place in the young person's life at the time, such as exams, relationships and peer pressures, and transitions from school to work, parental home to independent living, and so on. • Co-ordination of transitional care is critical, particularly for those with multiple specialty involvement, learning disabilities or other complex needs. In these cases, a co-ordinator should be identified to oversee each young person's transition. To ensure seamless transition, this person should either link with a counterpart within the adult service or remain involved until the young person is settled within the adult system. • Young people should be consulted and their wishes taken into account when choosing their transition co-ordinator. However, at present there are limitations to the availability of people with appropriate training/skills for this role, which is an issue that must be addressed. • It is recommended that a transition co-ordinator or key worker be nominated to manage the transition of young people from at-risk groups to adult services. • Continuity of care will be important after the patient has transferred to adult services. The transition co-ordinator must be able to commit to a period of continued involvement after transfer.

Transition Process and Transition Plan

You're Welcome. Quality Criteria for Young Persons Friendly Services (DH 2011)	• Health issues and transition for young people - this theme outlines the health needs of young people as they go through the transition into adulthood. It includes universal issues effecting all young people and issues effecting those with specific long term health needs • Appropriate staff members are trained to help young people, and their parents or carers, with the transition to adult services from the age of 12 onwards. All young people with ongoing needs have an individual transition plan. This will usually include a named key-worker for each young person who will provide continuity during the transition process. • The care and support of young people with complex needs are considered in the context of their cognitive ability and chronological age. This should include assessment of physical, psychological and emotional needs.
Diabetes – Quality Standards for Transition	**Transition Process** • Transition should be based on developmental readiness not chronological age. • Parents' needs must be considered in the transition process. • The young person, their parents and the professional should understand and reach agreement on each step of the process. • Transition should be introduced at around 12 years of age. - In order to prepare young people for the differences in services there should be regular discussions at appointments from 12 onwards. • It should take at least a year of joint consultation for the young person to transition into adult services. **Transition Plan** • Each young person should have a personalised care plan agreed with them. - The steps in the transition process should be available for young people and parents. These steps should be agreed with the adult service whether in the acute Trust or in the community.

Involvement of CHYP, Parent and Carers, including Self-care, Social Media and other methods	
Generic Specification for Transition	• Enable young people (and their parent carers) to become and remain active partners in their care. • Transition process should be supported by access to peer support which may be offered individually or in groups, face to face or through social media. • Promotes and enables self-efficacy, health literacy and self-management in a way that is developmentally attuned to the individual young person, their condition management and their wider health, psychological, social, educational and vocational outcomes. • Quality Standard 2 (2.2) Service improvement processes include the involvement and participation of young people and parent-carers. • Supported by access to multi -media resources with which young people want to engage and have been involved in developing. • Multi-media information resources relating to service provision, transition pathways, self-management and peer support available. • Quality standard 6 - A range of multimedia information and resources on transition to adulthood and adult health services, within the context of their specialist health needs, will be available and accessible to young people and their parent-carers. • All parent carers of young people have access to support and information in relation to their changing role as their son or daughter's transitions to adult services and lifestyles.
CQC Report	• Training and advice to prepare young people and their parents for the transition to adult care, including consent and advocacy. • CHYP, Parents and Carers must be involved in preparing for transition and their concerns, wishes, etc… must be included in transitions plans and other appropriate documents. • There was a lack of options or choices when appropriate services weren't available locally. • The needs of Parents and Carers must be assed and taken into account during the transition process. • Services should not just rely on parents, carers to navigate and often facilitate the transitions process.
NICE Draft Guidance	• Activities to ensure that young people are involved in, and informed about, the way that their transitions from children's services are planned and delivered. • Peers support groups. • Self-efficacy (young people's ability to undertake the activities they want to, as independently as possible). • Support for parents, families and carers of young people in transition. • What are the experiences of families and carers and in respect of young people's transitions?

Involvement of CHYP, Parent and Carers, including Self-care, Social Media and other methods	
Annex 1.Paediatric Medicine-Specialised Generic Children's Services Specification Insert	• Children, young people and their families are appropriately educated and enabled to manage their own illness as far as possible. • Children, young people and their families will be at the heart of decision-making, with the health outcomes that matter most to them taking priority. (The Outcomes Framework, NHS Mandate and Business plan.) • Children, young people and their families are asked for their feedback and services include a measure of patient experience and evidence this feedback has made a difference (You said... we did…). • Children, young people and their families have the opportunity to shape service change and improvement. • Also Friends and family test for CYP – 2015.
Lost in Transition - RCN	• Involving young adults in co-designing and co-producing services is an opportunity for all professionals to engage with young people to support them to manage their own care and treatment. Involving young people provides valuable information to help with planning and providing accessible and appropriate services. • Co-production and co-design have been successful models of engaging young people to manage their long-term conditions such as sickle cell disease. • Services should consider the possibility of adopting a mentoring scheme where a young person who has already undergone the transition may be able to offer help and support to other new arrivals. • The timing and duration of transition is negotiated with the young person and agreed by all relevant parties. • Young people are involved in the design of services for them – they take an active role and their recommendations are acted upon. • Teaching young people how to cope with transition is part of the transition process. • Online information can make a service more accessible and approachable. • The development and use of apps and social media is also an opportunity to co-design and engage adolescents. This has been particularly explored in conditions such as asthma and diabetes. • Parents or carers will have varying degrees of contact with, and responsibility for, the young person. It is important for key workers to understand this level of contact.
National Service Framework hospital standards (DH, 2003)	• A preparation period and education programme. During this time the young person will be helped to identify and develop the skills needed to achieve satisfactory transition to the adult clinic. A timed schedule for transition should be produced and written information provided.

Involvement of CHYP, Parent and Carers, including Self-care, Social Media and other methods	
Transition: getting it right for young people - Improving the transition of young people with long term conditions from children's to adult health services (DH 2006)	• Involve young people in service design and delivery: provide opportunities for young people to ask questions, express opinions and make decisions. • Set up a preparation period and education programme for the young person and parents.
Moving on Well (DH 2008)	• Transition planning should explore with young people, opportunities for independent living and developing skills in monitoring/managing their conditions and in developing and improving their self-image. • Advocacy and peer support. • Transition planning should be an evolving process in which a young person is gradually encouraged to take increasing responsibility and parents are able to adapt to changing needs. • The planning process needs to be based upon the young person's views about their health needs and how they may affect future choices, helping to identify the young person's goals and describe how the practicalities of transferring to adult services will be managed. • Health professionals taking the coordinating role should always work in partnership with young people, enabling them to increasingly take on coordination of their own health plan as they move into adult services. • A service responsive to the needs of young people and their families. • The opportunity to develop self-management and self-referral, as appropriate. • Provide opportunities in a suitable environment for young people with similar needs – especially those in mainstream schools – to share experiences and work on solving some of the problems they face. • Parents and carers may also need support as the young person takes on more independence and new challenges.
Think transition Developing the essential link between paediatric and adult care (Royal College of Physicians of Edinburgh Transition Steering Group, 2008).	• Peer support is immensely important to young people and plays a vital role in adolescent development. • Opportunities need to be introduced sensitively, however, because children's adolescence can provoke many emotions in parents such as loss, or fear, sparking a crisis in the parents' own emotional wellbeing. It is, therefore, essential that the needs of the parent(s)/carer(s) are taken into account during the transition phase. Their continued presence and participation in their child's healthcare is important, but care must equally be taken to ensure that they are prepared for the necessary changes that will evolve.

Involvement of CHYP, Parent and Carers, including Self-care, Social Media and other methods	
Think transition Developing the essential link between paediatric and adult care (Royal College of Physicians of Edinburgh Transition Steering Group, 2008).	• It is important that parents/carers understand the philosophy of transition, are aware of consent issues and of their child's rights to confidentiality, and so are prepared to work with healthcare professionals in achieving the best for their child. • Peer support is immensely important to young people and plays a vital role in adolescent development. • Include preparation for the self-management of the condition throughout childhood. • Provide access to learning for coping and self-advocacy skills.
Getting it right for children and young people. Overcoming cultural barriers in the NHS so as to meet their needs - A review by Professor Sir Ian Kennedy (September 2010).	• Local partnerships should recognise the value of, and consider ways to promote, 'social capital', including involving families and the wider community in promoting health and well-being for children and young people.
You're Welcome. Quality Criteria for Young Persons Friendly Services (DH 2011)	• Services across England need to take young people's needs into account. This includes primary, community, specialist and acute health services. • Young people's involvement in monitoring and evaluation of patient experience - This theme addresses the importance of capturing young people's experience of health services as part of service development, monitoring and evaluation. • Young people are routinely consulted in relation to current services and relevant new developments, and they are included in patient satisfaction surveys. Processes are in place to ensure that young people's views are included in governance service design and development. • The service invites and encourages all clients to give their opinions of the service offered and whether it met their needs; these are reviewed and acted on as appropriate. • Young people are routinely involved in reviewing local service provision against the Department of Health's Quality Criteria for young people friendly health services.
Diabetes – Quality Standards for Transition	• Young people must be invited to share their views about their diabetes service annually.

Professional and Workforce Development	
Generic Specification for Transition	• Provider's training directory identifies relevant training available and that core members of the health care team (or an MDT if established) MDT have been trained and receive training updates. • Delivered by staff who have undertaken training in providing health care for young people. • Quality standard 5 - All staff working with young people (13 -25) have received training on understanding the developmental needs and working in partnership with this age group. This may be as part of their core competencies in professional training or post qualification additional training.
CQC Report	• Adolescence/young adulthood should be recognised across the health service as an important developmental phase – with NHS England and Health Education England taking a leadership role. • Professionals must feel equipped to manage the transition process have good knowledge about age specific needs in relation to their complex needs.
NICE Draft Guidance	• Training of staff working with young people in transition, in children's and adult services and the effect of training.
Annex 1.Paediatric Medicine-Specialised Generic Children's Services Specification Insert	• All staff caring for children and young people are appropriately trained to look after children and young people and have appropriate communication skills. They have on-going continual professional development. • Children's community services are vital to deliver care closer to home. Teams need to be of an appropriate size to allow specialist and generic support in the community and allow an extended hours service. • There should be appropriate planning and training to deliver an appropriate children's workforce and this will change as new innovative roles are developed. • Professionals take every opportunity to "Make every contact count" to advise and sign-post children, young people and their families to enable them to improve their health and well-being outcomes. E.g. smoking cessation, pregnancy, social support, immunisations.
Lost in Transition – RCN	• Staff are designated within specialities to handle transitions. Such positions must be reallocated when the staff member leaves. • Making transition a significant part of a professional's Job description will ensure that the transition phase is not overlooked. • Transition roles are built into job plans, with role descriptions and selection processes. • All professionals and voluntary organisations are aware of each other's role in transition and the services offered. • Staff in all (particularly Children's and Adults) services are aware of the anxiety that the transition may create for young people and parents, and that sometimes young people's mental health may suffer as a result. • Transition is included in education and training, programmes for both adult services and children and young people's services. • All staff should receive training about the needs of the young adult facing transition.

Professional and Workforce Development	
National Service Framework hospital standards (DH, 2003)	• Hospitals will need to assess the needs of their staff for child specific education and training (document lists which areas the training needs to cover).
Transition: getting it right for young people - Improving the transition of young people with long term conditions from children's to adult health services (DH 2006)	• Professionals may need to consider further development of their knowledge and skills in working with young people, including: the biology and psychology of adolescence; communication and consultation strategies; multi-disciplinary and multi-agency teamwork; and an understanding of the relevant individual conditions and disorders and their evolution and consequences in adult life. • Train professionals in adolescent health in both paediatric and adult sectors.
Moving on Well (DH 2008)	• A skill mix which ensures that adolescent health expertise, professional/ clinical leadership, key working (where required) and supervision of support staff are available. • Analysing the current workforce in children's and adult services and challenging established patterns of provision, informed by the skill set needed to deliver agreed outcomes.
Think transition Developing the essential link between paediatric and adult care (Royal College of Physicians of Edinburgh Transition Steering Group, 2008).	• Recognition of the need for transition and the complexity of the process. • Knowledge of: – The physical and mental health needs of every adolescent, including health promotion and general health maintenance. – The legal rights and status of children and young people and of parents/guardians. – National and local health services accessible to young people. – The challenges and common behavioural responses of young people under stress. – The demands of education and society on young people. – An understanding of theories of resilience and self-efficacy as they apply to coping with chronic disease. – The educational theory that identifies learning styles and maturational readiness for self-directed learning • Consider the concept of transition in relation to the specific role of the chronic disease team. • All of those involved in the transition from paediatric to adult care, from both a clinical and managerial point of view, should seek to achieve a "reflective awareness" of the ethical issues involved in this transition in a manner best suited to their individual circumstances; Sufficient opportunities to achieve such a "reflective awareness" should be available in the contexts of undergraduate training, postgraduate training and in continuing professional development.

Professional and Workforce Development	
Getting it right for children and young people. Overcoming cultural barriers in the NHS so as to meet their needs - A review by Professor Sir Ian Kennedy (September 2010).	• To address the challenge of transition, there should be a cadre of professionals who are trained in both paediatrics and the care of young adults, putting the young person at the centre and addressing the needs of 16- to 25-year-olds. • All GPs, practice nurses and other professionals attached to general practice or who form part of a polysystem should, as a matter of urgency, receive training in the comprehensive care of children and young people. • The initial training for GPs, the Quality and Outcomes Framework and the system of revalidation should all incorporate the need for training in the comprehensive care of children and young people. • Government, employers and professional groups must address the need for more professionals trained in the range of skills required in the comprehensive care of children and young people as a matter of urgency. • There should be joint training of professionals involved in the care and welfare of children and young people, according to agreed curricula, particularly in the area of safeguarding. • There should be a cadre of professionals who are trained in both paediatrics and the care of young adults. Government, employers and professional groups should work together in order to ensure that such a cadre is established and receives appropriate training.
You're Welcome. Quality Criteria for Young Persons Friendly Services (DH 2011)	• Staff training, skills, attitudes and values - This theme addresses the training, skills, attitudes and values that staff need to deliver young people friendly services and ensuring the needs of young people are met. Local Authorities and commissioners of NHS and public health services have an important role to play in providing/ co-ordinating advice on training and safeguarding arrangements. • Appropriate staff members are trained to help young people, and their parents or carers, with the transition to adult services from the age of 12 onwards.
Diabetes – Quality Standards for Transition	• The professionals involved in transition should demonstrate an interest in young peoples' health and wellbeing. - Professionals should have received appropriate training in how to communicate with young people e.g. e-learning for health and tools such as motivational interviewing. A process should be in place to get feedback from young people on each professional's communication skills. The GMC has a patient feedback questionnaire1.

Health Settings & Services, including primary care.	
Generic Specification for Transition	• The G.P. is acknowledged as a key professional to involve and inform particularly at the point of transfer if the young person has complex needs and will require continuing care from other health or social care services. • Transition care pathway which has been co-designed by paediatric and adult services, young people and their parents and carers. • Care pathways must be shared with Primary Care to ensure GPs have the relevant information to support young people (and their parent carers) during and after transition. • All health care organisations providing the specialist health care services as defined in the NHS England Manual should have an organisation wide transition policy and a named professional responsible for assuring its implementation and review.
CQC Report	• Health services provided in an appropriate environment that takes account of their needs without gaps in provision between children's and adult services. • More coordination is needed across children's and adult's health services regarding transition, (adult service must be involved when the process begins). • Adult service need to provide appropriate care for CHYP who are transitioning. • GPs should be more involved, at an earlier stage, in planning for transition. (General practice has a crucial role as the single service that does not change as a result of reaching adulthood.) • Pathways must be in place for between services for the transition of CHYP from Children's to adults.
NICE Draft Guidance	• Continuity of care implications for continuity: loss of contact with services, lack of appropriate referral • Promotion of continuity of care: satisfaction, inter-agency communication, clinical outcomes.
Annex 1.Paediatric Medicine-Specialised Generic Children's Services Specification Insert	• When a Young Person is transitioned to adulthood some conditions may be looked after in primary care or a GP may be requested to help with the palliative care of a patient. They often prescribe many of the medications. It is important therefore that the GP is kept fully informed and they are given appropriate information about the child or young person's illness and clear guidelines to the expectations from you. • Children with long term conditions should have a named GP.
Lost in Transition – RCN	• Services need to be flexible and based on the needs of the young person, rather than focused on the needs of the service. • Service providers should examine the way transition services are delivered. Services may need to be redesigned so that they truly meet the needs of this client group.

Health Settings & Services, including primary care.	
Lost in Transition – RCN	• In order to reduce missed appointments, and so that young adults are engaged in their own treatment, services should be accessible and acceptable to these patients. • All services use means of access and venues which suit young people, in tertiary, secondary and primary care settings. • Where children and young people are admitted to adult inpatient areas, full consideration is given to child protection issues. • When a young person fails to attend appointments, professionals should explore why, and if necessary consider different methods of access for them. • Adult service colleagues understand young people's issues, needs and risk areas.
National Service Framework hospital standards (DH, 2003).	• Tertiary service's will need to work together with a lead local clinician on behalf of local children's services and primary care to set up referral protocols and arrangements for local service provision including transition planning into adult care for LTCs, an interested and capable adult clinical service, which has close links with the children's service, an understanding of the developmental needs of young adults, and participates actively in the transition. Individual specialist disciplines such as diabetes, epilepsy, rheumatic disease, and congenital heart disease, should provide specifically for the needs of young people, and, where numbers justify, develop a separate young people's service. They should also ensure that social, psychological; education and employment needs are addressed. • Hospital care of children and young people should be provided in buildings that are accessible, safe, suitable, and baby, child and family-friendly. • Children should not be cared for on adult wards, but on wards that are appropriate for their age and stage of development. Actual age is less important than the needs and preferences of the individual child or young person. (Document looks at this in further detail).
Transition: getting it right for young people - Improving the transition of young people with long term conditions from children's to adult health services (DH 2006)	• Appropriate environment, adolescent in-patient unit should be provided but this will not always be the case and flexible approaches should be available, Out-patient clinics should have a décor appropriate to this age-group and these requirements should be incorporated in planning (Even when resources are not readily, identifiable, including these environmental issues in policies, plans and, procedures ensures they are not forgotten). • Identify interested and capable adult services, a transition programme can only be successful if organised with the active participation and interest of the receiving adult service. • Ensure primary care involvement primary care staff should be invited to participate in transition planning and may be able and eager to coordinate the young person's future medical care.

Health Settings & Services, including primary care.	
Moving on Well (DH 2008)	• Negotiate administrative support Institutional and management support need to be assured at both ends of the transfer chain. Casual agreements between doctors, while easy to set up, are prone to failure. Policies and transition protocols need to be agreed at appropriate meetings and receive management support. • Health representation on local transition strategy groups. • Excellent links across adult and children's services. • Young people (and their families on their behalf) using primary care appropriately. • Age-appropriate settings where young adults can receive their care from health professionals.
Think transition Developing the essential link between paediatric and adult care (Royal College of Physicians of Edinburgh Transition Steering Group, 2008).	• Paediatric and adult medical teams play key roles in meeting the challenges of transition. • Hospital youth workers, though thin on the ground, are an excellent resource to access if help is needed in developing peer support groups. • Local council youth workers can be very supportive in any healthcare setting and can continue their involvement with young people into their twenties, i.e. after transfer to adult services. • The adult service should have an understanding of the developmental needs of young adults and participate actively in transition. • Individual specialist disciplines should provide specifically for the needs of young people and, where numbers justify, consider developing a separate young people's service. • Regardless of whether or not GPs are nominated as transition co-ordinators, their relationship with the young people and their families should be fostered during the transition process (and, indeed, from much earlier on), particularly in the case of young people with significant neuro- and/or learning disabilities.
You're Welcome. Quality Criteria for Young Persons Friendly Services (DH 2011)	• The Department of Health Quality criteria for young people friendly health services are based on examples of effective local practice working with young people aged under 20. They should be applied to general and acute health problems, chronic and long-term disease management (such as specialist care for asthma and diabetes) and health promotion. • **Accessibility** - This theme outlines how to ensure that services are accessible to young people • **Environment** - This theme addresses the service provision, environment and atmosphere, with the aim of ensuring that they are young people friendly (at the same time as being welcoming to all service users, regardless of age). The 'environment' is taken to include the atmosphere created by physical arrangements as well as staff attitudes and actions. The environment can contribute to ensuring confidentiality for service users.
Diabetes – Quality Standards for Transition	• Transition clinics and in patient care should take place in a young person friendly environment.

Guidance & Protocols	
Generic Specification for Transition	• Named executive lead for transition. • Transition policy covering services for young people (13 -25) developed, implemented and reviewed annually with assurance report to the board and commissioners. • Compliance with You're Welcome Quality Standards for young person appropriate services. • Transition Steering Group led by named executive lead for transition monitors, reviews and improves compliance with NHS England Generic Transition Specification and any other commissioned outcomes / quality standards relating to transition. • Transition pathway and operational guidelines jointly developed by Paediatric, TYA / Adult services and service users implemented. - Published pathway and guidelines available to staff, young people and parent carers using the service. • Quality standard 1 - The provider (Trust /Service) has a documented transition to adulthood and adult health services policy developed and reviewed with key stakeholders.
CQC Report	• Guidance that is in place must be used and all staff must be aware.
NICE Draft Guidance	• Organisational frameworks for transition.
Lost in Transition - RCN	• There should be a shared protocol between children's and adults' services, which is a genuinely shared arrangement, and is properly implemented. • To ensure effective and seamless transition, each health care area has agreed, accessible and known transitional care arrangements.

National Service Framework hospital standards (DH, 2003).	• Every trust dealing with young people should have a policy on transition to adult services.
	• Every paediatric general and specialty clinic should have a policy on transition to adult services which should be the responsibility of a named person, covering:
	  • A policy on timing of transfer
	  • A preparation period and education programme.
	  • A co-ordinated transfer process.
	  • An interested and capable adult clinical service,
	  • Administrative support,
	  • Primary health care and social care involvement,

Guidance & Protocols	
Transition: getting it right for young people - Improving the transition of young people with long term conditions from children's to adult health services (DH 2006)	• Monitoring and "fail-safe" mechanisms, a formalised transition checklist is helpful. There must be a failsafe mechanism that ensures that the young person is regularly attending the adult clinic and has not defaulted or failed to attend or been lost to the system. • An agreed process for joint strategic planning between children's and adult health services. • A clear transition care pathway.
Moving on Well (DH 2008)	• The transition process should be facilitated by inter-agency sharing agreements. • Integrated multi-agency health transition plans and pathways which enhance a young person's ability to take appropriate responsibility for managing their own health needs, promoting choice and opportunities for independent living. Plans must take into account the young person's transition from school to college, training or employment. • Risk management procedures including effective follow-up for vulnerable young adults, Multi-agency protocol for risk management in complex team-working situations. • Development of multi-agency transition protocols.
Think transition Developing the essential link between paediatric and adult care (Royal College of Physicians of Edinburgh Transition Steering Group, 2008).	• As the transition process spans paediatric and adult services, a transition policy that sets out what is expected and involved in the process is essential. • One of the components of any policy advocated should be access to an interested and capable adult clinical service, which has close links with the paediatric service.
You're Welcome. Quality Criteria for Young Persons Friendly Services (DH 2011)	• There is a written policy on confidentiality and consent to treatment and the policy is consistent with current DH guidance. The policy includes a clear protocol for the Safeguarding concerns and possible breaches of confidentiality. • The service has a clear procedure to prepare young people for the transition from health services designed for children and young people to adult health services, consistent with current Department of Health guidance. Specific attention is given to the needs of young people with long-term health needs.
Diabetes – Quality Standards for Transition	• A clear policy for young people who have more complexity in their care plan is needed.

Quality, Data, Performance and outcomes (including CHYP Service experience measures)	
Generic Specification for Transition	• Provider data base identifying population of 13 – 25 year olds within commissioned specialist services with transition plans identified and accessible via PAS and EPR systems. • DNA rates for 13 – 25 year olds tracked and managed by responsive DNA policy (and involvement of GPs in the DNA policy). • Patient safety incidents relating to care of young people, particularly peril-transfer, extracted, collated and reviewed for trend analysis and action plan shared learning. • Quality standard 2 (2.1) - All services provided for young people (13 – 25) routinely evaluate and improve the quality of their service based on annual You're Welcome assessments and Patient Surveys. • The use of patient safety incident reporting to assess and address failures in the transition pathway. • Patient –Led Assessments of the care environment (PLACE) assessments undertaken by young people in conjunction with Young People Friendly / You're Welcome assessments. • Patient survey data for young people (Picker Questionnaire in development) filtered by specialist service.
NICE Draft Guidance	• NICE Guidance developed in the context of You're Welcome. • Experience of care, for example, accessibility and acceptability of services.
Annex 1.Paediatric Medicine-Specialised Generic Children's Services Specification Insert	• Planning and development of services takes into account number of staff required to treat number of patients. • Healthcare is delivered to the same standard 24/7. • Staff are able to access, understand and act on service activity and outcomes. • Good quality information is collected and used to inform service planning. • Staff are able to access and act on information on service activity and outcomes. There is evidence that minimum data sets are collected and incidents are reported and acted on. • Services should bench mark themselves against each other and variations in care should be explored and understood. Good practise should be shared and unnecessary variation reduced. • There should be included mechanisms to act on incidents across pathways of care and evidence of audit and re-audits preferably across pathways. • All those involved in the care, treatment and support cooperate with the planning and provision to ensure that the services provided continue to be appropriate to the age and needs of the person who uses services. Consideration should be made to young people.

Quality, Data, Performance and outcomes (including CHYP Service experience measures)	
Transition: getting it right for young people - Improving the transition of young people with long term conditions from children's to adult health services (DH 2006)	• Children's and adult health services should agree the best way of measuring the effectiveness of transitions arrangements. One example of an indicator used to do this is to measure over time the "did not attend" (DNA) rate for young people at their second adult service appointment.
Moving on Well (DH 2008)	• Review of the transition process and outcomes for young people. • Better long-term health and wellbeing, access to education/employment and improved social inclusion. • A reduction in health inequalities. • Reduced risk of poor health outcomes. • Identified quality standards to enable performance management. • Measurable outcomes to ensure a value-for-money service. • Knowledge of the number of young people who will require transitional support and the nature of their health needs including those in out-of-area placements, 'looked-after' children and those without statements of SEN. This knowledge needs to be linked to local authorities' data collection to enable the sharing of basic information while protecting individual confidentiality, through the Integrated Children's System supported by the Common Assessment Framework • Monitoring and evaluation of health transition provision needs to recognise what is important to people using the service. • Review health planning process and access to relevant services. • Track outcomes for individual young people via health plans. • Audit service quality and provision within a multi-agency context, using both quantitative and qualitative measures. • Analyse waiting times and gaps in service in relation to needs assessment. • Evaluate feedback from service users, practitioners and (multi-agency) transition teams. • Identify successful and innovative practice. • Outcome measures might include 'clinical outcomes improved/maintained', 'young person/family satisfied with care' or 'young person able to access adult services successfully', as well as measures of personal development.

Quality, Data, Performance and outcomes (including CHYP Service experience measures)	
Getting it right for children and young people. Overcoming cultural barriers in the NHS so as to meet their needs - A review by Professor Sir Ian Kennedy (September 2010).	• Data sets must be agreed as a matter of urgency by the NHS and government covering the range of services provided to children and young people by the NHS and data must be collected, analysed and disseminated to those who need it within the local partnership. The data must allow services to be held accountable for the quality of the outcomes achieved. • There should be a single criterion for measuring the quality of the NHS's services for children and young people – satisfaction. • There should be two elements to satisfaction: whether children and young people are satisfied with the outcome achieved, by reference to what they are able to judge; and whether the professional should be satisfied, by reference to the current appropriate benchmarks of performance. The internal performance management and external regulation of the NHS must reflect this approach.

Communication and Information	
CQC Report	• Robust information provided for CHYP and their parents/carers about changes they can expect from into adult services. • Information must be clear and available regarding transition arrangements and services available.
Annex 1.Paediatric Medicine-Specialised Generic Children's Services Specification Insert	• Children, young people and their families feel listened to and have meaningful information provided to them in a format that empowers them to make informed choices. • Health information is provided in a format that is easy for them to understand and is age appropriate. • Patient information is shared with informed consent between health, social care and education. • Information systems and technologies are in place to facilitate the easy and secure sharing of information and communication. • Good quality information is collected and used to inform service planning • All children and young people who use services must be: - Fully informed of their care, treatment and support - Able to take part in decision making to the fullest extent that is possible. - Asked if they agree for their parents or guardians to be involved in decisions they need to make.
Lost in Transition - RCN	• Preparing the young person for transition includes explanation and, where possible, visits to the new clinic settings. Where young people will be exposed to adult. • Clinical inpatient settings, preparation should include helping young people to understand how some patients • May behave, so that they feel less anxious if they encounter difficult or frightening behaviour. • It is important for key workers to understand to agree appropriate communication channels in collaboration with the parents/carers and the young person. These discussions must include issues of confidentiality. • The young person understands how and when therapeutic contact will come to an end in one service, and agrees this with transition key workers. • People undergoing health transitions should have access to and advice about appropriate support, such as education advice and health education. • Issues of confidentiality between professionals, young people and parents to be discussed and the outcome to be clearly documented.

Communication and Information	
Transition: getting it right for young people - Improving the transition of young people with long term conditions from children's to adult health services (DH 2006)	• Provide accessible information about services. • What happens in the consulting room - the triad of communication between parent, young person and professional - is key, Doctors often think the parents inhibit the child from speaking for themselves – but parents complain about doctors who ignore the young person and only speak to the parent.
Moving on Well (DH 2008)	• Information sharing and confidentiality. • From the start of the process, professionals must work with the young person and their family to ensure that, with their permission, information is shared to inform each other's assessments and coherent planning is based on a real understanding of the young person's needs. • Sharing of information between the young person and health professionals involved in their care and treatment is critical to successful transition. • Information shared with and between health professionals enables a consistent approach to the young person's care and treatment. • Strategies for young people and their families, providing information packs relating to the specific condition, including contacts for local/national support groups and sources of advice, can be helpful to support health plan discussions. It is also useful to give out the local multi-agency transition guide for young people/parents. • Health included in multi-agency guides to local transition resources for young people and families.
Think transition Developing the essential link between paediatric and adult care (Royal College of Physicians of Edinburgh Transition Steering Group, 2008).	• Good communication is vital, and the manner in which doctors and other healthcare staff communicate with young patients is important to the relationship they build. • Accurate, age-appropriate information is essential. Allocate dedicated time for education sessions. • Ensure young people's awareness of their legal rights as a child and as an adult, and awareness of issues around consent and confidentiality. • Provide appropriate knowledge about the young person's disease, its management and their responsibility for their own health • Prepare for transition with accurate information about adult services, including team structure and any important differences in practice. Allow adequate time to identify concerns and to address them, as well as rehearsal for adult clinic attendance – routines, personnel, administration, etc.

Communication and Information	
Think transition Developing the essential link between paediatric and adult care (Royal College of Physicians of Edinburgh Transition Steering Group, 2008).	• How to use an independent advocate if the young person chooses to do so. • How to access any recommended personal or internet peer support groups. • Ensure parents are aware of the legal rights of their child, their responsibilities as parents and the changes that apply with age and their child's legal capacity. • Prepare parents for letting go and accepting their child's healthcare decisions.
You're Welcome. Quality Criteria for Young Persons Friendly Services (DH 2011)	• Publicity - This theme highlights the importance of effective publicity in raising awareness of the services available and explaining the extent of confidentiality. Effective publicity enhances access. • Confidentiality and Consent - Confidentiality and consent policies are made explicit to young people and parents or carers. All staff routinely explain the confidentiality policy to young people and to their parents or carers in order to enable them to understand young people's right to confidentiality. • The service provides publicity material specifically outlining the transition to adult services. This material is attractive to young people and is presented in a way that is young people friendly. • In order for parents/carers to discuss health issues with young people, they are provided with relevant information and support, in ways that are sensitive to different cultures and religions.

NHS England

Strategic Clinical Networks and Senate
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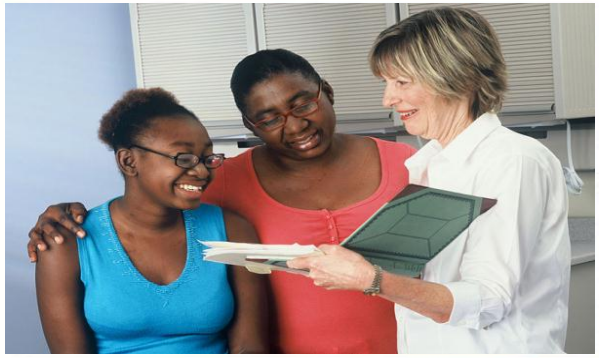

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the NHS belongs to us all