

(Supplementary material)

Selected resources that may aid designing and maintaining transitional services.

Web site	Description	Useful to
TRAINING RESOURCES		
http://www.unil.ch/euteach/home.html	Provides objectives, strategies and resources for trainers and teachers.	Healthcare professionals
http://www.e-lfh.org.uk/programmes/adolescent-health/	The Adolescent Health Programme (AHP) is an e-learning programme for all healthcare professionals working with young people.	Healthcare professionals
http://www.talklab.nhs.uk	TalkLab's Better Conversations programme aims to improve the sometimes complex, three-way consultations doctors have with young people and their parents	Health care professionals, young people and families
http://www.usc.edu/adolhealth/	This site was developed for use by health care professionals involved in either the teaching of adolescent health or clinical care of adolescents and young adults. The material includes cases, questions, weblinks and references.	Healthcare professionals
GUIDANCE		
http://www.cps.ca/en/documents/authors-auteurs/adolescent-health-committee#practice-points	This website provides health professionals information needed to make informed decisions about the well being of children and youth. Parents, journalists and other stakeholders may also find this site useful.	Healthcare professionals, young people and families.
http://www.adolescenthealth.org/Clinical-Care	This site provides resources to adolescent and young adult health	Healthcare

Web site	Description	Useful to
Resources/Clinical-Care-Resource-Guides.aspx	care providers and youth serving professionals. Include clinical care guidelines and resources. Most of the resources included are applicable in the U.S. and some are internationally applicable.	professionals, young people
https://www.nice.org.uk/guidance/ng43	This guideline of the National Institute for health and Care Excellence includes recommendations for transition.	Healthcare professionals, young people and families.
PROFESSIONAL ORGANISATIONS		
http://www.yphsig.org.uk/	Home page of the Young People's Health Special Interest Group of the Royal College of Paediatrics and Child Health, UK	Healthcare professionals
http://www.adolescenthealth.org	Home page of the Society for Adolescent Health and Medicine	Healthcare professionals
http://www.iaah.org	Home page of the International Association for Adolescent Health	Healthcare professionals
TRANSITIONAL CARE RESOURCES		
http://www.gottransition.org/	Include a complete compilation. Serve as a clearinghouse for current transition information, tools, and resources. Also in Spanish.	Healthcare professionals, young people and families.
http://depts.washington.edu/healthtr	Include transition resources such as websites, checklists and tools for teens and young adults with disability or chronic illness.	Healthcare professionals, young people and families.
http://chfs.ky.gov/ccshcn/ccshcntransition.htm	Interesting website with Transition Resources, ages adapted	Young people and

Web site	Description	Useful to
		families
http://www.chla.org/my-voice-adolescent-transition-program	Include information about Adolescent Transition Program	Young People and families
http://www.floridahats.org/	A health care transition tool box contains documents and links to a variety of local, state and national resources. Materials for youth, families and professionals are organized in several categories.	Healthcare professionals, young people and families.
http://www.sickkids.ca/good2go/	This site provides resources to youth, families, and health care professionals.	Healthcare professionals, young people and families.
http://www.ontracbc.ca/	Includes information about transition: preparation, transfer, and attachment to adult services. Includes toolkits for youth, parents/families, and care providers	Patients, families and health care professionals
http://www.transitionfonetwork.org.uk	Provides information about the transition process that is useful to disabled young people, parents/carers and professionals.	Healthcare professionals, patients and families.
http://www.chimat.org.uk/transitions	Resources and evidence relating to young people's transition process into the adult world. It is regularly updated	Healthcare professionals, patients and families.
http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx	Description of the Ready Steady Go transition programme. Include resources for health professionals and useful links	Young people, families and health care professionals

Web site	Description	Useful to
http://www.rch.org.au/transition/	Transition Support Service of Royal Children’s Hospital Melbourne, Australia. Includes fact sheets and tools, links, publications and others.	Healthcare professionals, young people and families.
RHEUMATOLOGY-SPECIFIC		
http://www.bspar.org.uk/adolescent-rheumatology	Excellent website of British Society for Paediatric and Adolescent Rheumatology Include a complete compilation of useful resources for young people and professionals.	Healthcare professionals, young people and families
Paediatric Musculoskeletal Matters http://www.pmmonline.org	Free website explaining the essentials of rheumatic diseases in children and young people and useful for support and training of shared care providers.	Health care professionals
http://www.healthtalk.org/young-peoples-experiences/arthritis/transition-moving-adolescent-or-adult-services	This website provides free, reliable information about health issues, by sharing people's real-life experiences.	Young people
http://www.jatransition.org/	Website designed to prepare youth with rheumatic diseases and their families for the transition to healthy adulthood.	Young people and families
http://www.arthritisresearchuk.org/youngpeople	Includes practice information for young patients, parents and also for patient school teachers.	Young people and families
http://www.jia.org.uk/transition	Include useful resources about moving from paediatric to adult care. Includes a specific guide for parents	Young people and families
http://www.kidsgetarthritisoo.org/living-with-ja/daily-life/transition/	Specifics resources for parents.	Families

Web site	Description	Useful to
http://www.hopkinsarthritis.org/patient-corner/transitioning-the-jra-patient-to-an-adult-rheumatologist/	Explanation about Transitioning the JRA Patient to an Adult Rheumatologist: patient view	Young people
http://www.jong-en-reuma.nl/	Website created for and by young people with rheumatic diseases. In Dutch	Young people
http://www.reuma-uitgedaagd.nl/	Information for young people with rheumatic diseases. In Dutch	Young people

Standards at national level

1. Adolescent and young adult care (including transition) is included in national training syllabuses (adult + paediatric) for all allied health professionals and doctors in adult and paediatric rheumatology.
2. There is adequate IT infrastructure to facilitate communication between paediatric and adult rheumatology teams.

Standards at unit level (minimum + ideal)

1. There is a professional with a designated role for transition (i.e. 'transition coordinator') working between paediatric and adult rheumatology services
2. There is a written transition policy agreed with paediatric and adult rheumatology networks and their supporting infrastructure (e.g. management teams, insurers, etc)
3. There is a clinical transfer summary template agreed by paediatric and adult rheumatology
4. There is adequate IT infrastructure to facilitate data collection, recording of outcome and quality indicators, and facilitating communication between paediatric and adult rheumatology teams
5. There is evidence of young people being actively involved in service design and development
6. There is a research programme on transition and adolescent and young adult care

Standards at patient level (minimum + ideal)

1. The YP attends the first two appointments in adult rheumatology
2. The YP receives a clinical transfer summary produced by paediatric rheumatology and agreed by the young person, and this is received by adult rheumatology and primary care provider for every YP
3. Outcome measures:
 - a. achievement of transition readiness,
 - b. disease knowledge,
 - c. improved medication adherence
 - d. disease control
 - e. quality of life
 - f. Participation
 - g. young person or family satisfaction
 - h. self advocacy

- i. self-management readiness
- j. resilience / independent living
- k. work stability and employment

Quality indicators

To test in the setting before and after the implementation of the health service.

1. % Lost to follow-up after 1 year of transfer
2. % no shows on visits in adult rheumatology after 1 year of transfer
3. YP and family satisfaction with transfer process (e.g. Mind the Gap scale)[63, 89, 90]
4. Satisfaction of members of the MDT
5. The proportion of YP with a complete transfer document
6. The number of contacts documented in the year before and after transfer for each YP
7. An agreed written policy is in place
8. The proportion of MDT staff completing the transition training programme
9. An IT platform is available to host resources, tools, guidelines and policy documents
10. Outcome measures:
 - a. achievement of transition readiness
 - b. disease knowledge
 - c. improved medication adherence
 - d. disease control
 - e. quality of life
 - f. Participation
 - g. young person or family satisfaction
 - h. self advocacy
 - i. self-management readiness
 - j. resilience
 - k. independent living
 - l. work stability and employment

Suggested content and format of communication at different levels of transitional care.

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| <p>1) Communication between health professionals and patient:</p> <ul style="list-style-type: none">a) Developmentally-appropriate language, YP-oriented<ul style="list-style-type: none">i) honest, realistic and jargon freeii) supportive dialogueiii) assisting young people to develop the communication skills that are necessary to manage and navigate services effectivelyiv) establishing a positive therapeutic relationship that enables young people to express opinions and make informed decisions about careb) Offering opportunities (enough time, independent of caregivers/parents, appropriate environment, talk to peers) for communicationc) Developmentally-appropriate format (written, verbal, phone calls, emails, texting, referring to other forms of communication),d) Explain and assure confidentiality (e.g. before discussing sensitive topics) |
| <p>2) Communication between health professionals and family:</p> <p>It must be in a format that can be understood, and family-oriented:</p> <ul style="list-style-type: none">i) appropriate verbal and non-verbal communicationii) referring to other forms of communicationiii) acknowledging parents knowledge base and pivotal role in caringiv) offering available supporting servicesv) respect rights to confidentiality of the young person |
| <p>3) Communication between health professionals:</p> <p>The members of the adult and paediatric rheumatology teams will have direct contact as a minimum by telephone or email before the handover of the young person, and document it. There should be at least two direct contacts between the paediatric and adult rheumatologist during the process of transition:</p> <ul style="list-style-type: none">i) one member of the paediatric team: announcing transfer of patientii) one member of the adult team: feedback confirming that the patient has been seen for at least the first two visits in adult care. |