The MAGICC and practical approach to rheumatology transition

This article describes the inception and continuing evolution of a seamless adolescent rheumatology service across a children's and adult hospital. This service is still a work in progress but its principles are embedded in the MAGICC approach: Moving on in adolescence, Growing up In Collaboration and Coping.

With improved survival of children with chronic illnesses, there is a new and increasingly important health-care dimension; the young adult with disabilities or diseases attributable to conditions of childhood and adolescence. Understanding what is 'special' about adolescence is crucial in tailoring services (including transition) appropriately and involving young people in their care. This article gives an overview of available best evidence about transition and adolescence, contextualizing this with a practical description of professional and patient experiences of setting up a rheumatology transitional service.

The need for transition

Young people aged 10–19 years are defined as adolescents (World Health Organization, 2002), young adults are those aged 16–25 years and collectively this group are termed adolescents and young adults. In the UK today, adolescents are a significant proportion of the population, comprising 13–15% of the total and outnumbering those aged 0–10 years. With reducing mortality and increasing health it is predicted that this group will continue to grow (Royal College of Paediatrics and Child Health, 2003). Worldwide, there are 1.2 billion adolescents with often unrecognized and unmet health needs (United Nations Children's Fund, 2012).

Adolescence in healthy young people is a demanding time of change physically, emotionally and socially. Adolescents with chronic illness are in the unenviable position of having to figure out who they are, their role within their society and their world, but also having to deal with the impact of their illness on a daily basis, alongside potential repercussions on their education, future career and relationships (Maslow et al, 2011). They must move, and cope with moving, from paediatric care to adult care and therefore are not only in transition from childhood to adulthood, but in situational transition, from the care of the paediatric team to the adult health-care team.

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Simply discharging children and young people from paediatrics to counterpart adult services causes disengagement of young people from their health care and consequent morbidity (Watson, 2000; Nakhla et al, 2008). Recognition from health-care providers that adolescents require a multidimensional, tailored approach is well established with advocates for adolescents providing a strong voice to guide health-care providers on the needs of adolescents and young adults (Viner, 2008, McDonagh et al, 2006a). One solution in addressing the needs of this unique and complex group is the planned process of transition to facilitate transfer of care between services, where transition is defined as:

> **'the young-person centred process of addressing the medical, psychological, educational and vocational issues as young people with chronic conditions move from child-centred to adult-centred care' (Blum et al, 1993).**

The challenge of providing tailored and adolescent-friendly services, within which effective transition processes are embedded, has led policy makers and professional bodies to publish guidance for health-care providers (Department of Health, 2006; Hargreaves, 2011) and led to discussion about transition among professionals (Tattersall and McDonagh, 2010). Key is the understanding that young people should only transfer care from paediatric services when they are ready and have the required skills to negotiate adult medicine. For health-care professionals, this requires an appreciation of, and skills in, adolescent medicine and, crucially, working knowledge of what distinguishes adolescence from childhood and adulthood. Training in this important area is lacking in both paediatric and adult medical domains (Ercan et al, 2008). Despite recognition of the need for transitional services, progress across many specialities has been slow. Ongoing barriers to implementation of transition services have also been outlined (Department of Health, 2010; American Academy of Pediatrics et al, 2011; Price et al, 2011a, b), and the authors discuss later in this article how some of these barriers affected their own service and its development.

What is so special about adolescence?

Adolescence is the developmental period where dependent children move to become independent adults with developmental tasks such as biological and emotional

maturation and the development of personal autonomy (Christie and Viner, 2005). While puberty and physical growth during adolescence is well characterized, neurocognitive development which continues into the early twenties is critical. This occurs particularly in the brain's frontal lobe where 'executive' functions, such as abstract and long-term reasoning, reside (Johnson et al, 2009; Steinberg, 2010). Therefore, a particular vulnerability of adolescence is in the combination of physically mature bodies with relatively immature brains making adolescence like 'starting the engine without a skilled driver at the wheel!' (Steinberg, 2005).

Key to this brain development is the hallmark exploratory or 'risk-taking' behaviour (such as experimenting with smoking and alcohol) which is normal and can be expected in adolescence. These behaviours can be challenging for families and carers, as well as health-care professionals. Risk-taking behaviours tend to cluster together and are associated with non-compliance with medical advice (Lurie et al, 2000; Suris et al, 2008). While adolescent issues comprise significant workloads for health-care professionals, many feel ill-equipped and ill-trained to deal with risk-taking behaviours, adolescent communication and transition-specific issues (McDonagh et al, 2006b). Training the authors' team in adolescent-specific issues has been key in delivering a tailored adolescent service and continues to be an important issue.

Planning transitional services

There is surprisingly scarce available evidence on transition implementation and evaluation given the complexity of adolescence and multiple policy documents. There is, however, a literature both on the slow progress in achieving transition planning across many specialities as well as the specific barriers to their implementation. *Table 1* summarizes these barriers. The authors have struggled with some of these issues and discuss some of their solutions later on.

Of the available evidence on transition implementation, there are some clear pointers towards the importance of dedicated young people's clinics, joint clinics of paediatric and adult health-care professionals, educational programmes and possibly the role of a transition coordinator (Crowley et al, 2011; Lugasi et al, 2011; Sable et al, 2011). A notable and positive exception in this gap is in rheumatology and specifically the work of Janet McDonagh and the British Society of Paediatric Rheumatology. This group used a multicentre trial to study the implementation of a coordinated transitional care programme built around core principles identified from their previous work (McDonagh et al, 2006a, 2007). This intervention improved the health-related quality of life of young people with arthritis who went through the programme. In subsequent work reflecting on the applicability and generalizability of such a study (McDonagh, 2008), key components around which to build a transitional service (*Table 2*) and the skills the service should aim to help young people to develop to negotiate their own health care in transitional services (*Table 3*) were identified.

Table 1. Barriers to successful transition

Psychosocial barriers of the patient or parents	Fear and reluctance of the patient and/or parent
	Parent or carer resistance to growing independence of their adolescent (fear of loss of their carer role)
	Lack of confidence in patient in developing self-advocacy skills
Psychosocial barriers of the health-care providers	Reluctance of the paediatrician to 'let go'
	Lack of adolescent-friendly communication skills of professionals
	Lack of training in adolescent health in paediatric and adult physicians
Service barriers	Poor transition planning and coordination of paediatric and adult services
	Lack of established relationships between paediatric and adult services
	Lack of educational programmes for preparing patients in 'readiness' for transfer and development of self advocacy skills
	Lack of time in clinic to allow for individual adolescent approach
	Lack of established transition plans
	Split sites of paediatric and adult services
	Lack of age-appropriate facilities
	Lack of key coordinators to help families through the transition process
	Engagement of primary services in transition process
	Lack of recognition of need for investment by staff and management in the transition process

Table 2. Key components of a transitional service

Written policy across paediatric and adult medicine
Early, planned process
Well documented
Delivered by trained professionals
Geared to helping young people develop their resilience, i.e. their knowledge and skills acquisition for managing their own health care
Service involves young people
Service continually evaluated, audited and modified

Table 3. Key skills to help young people develop to negotiate their own care in transitional services

Communication
Decision making
Creative problem solving
Assertiveness
Self care
Self determination
Self advocacy

Transition is a crucial bridge between paediatric and adult rheumatology and yet is often not a priority in either discipline. Transitional work is not 'new' work – young people with rheumatic disease are seen in paediatric and adult rheumatology services as they always have been, but reorganizing this work into transitional pathways offers an opportunity to do this work better, more efficiently, with more job satisfaction and without increasing cost. Illnesses such as systemic lupus erythematosus and enthesitis-related arthritis present particularly severely in adolescence and this has also influenced service development. In particular the authors have liaised closely with colleagues in adult rheumatology with a combined continuing educational programme meeting and a combined adult and paediatric rheumatology team meeting to ensure that whether adolescent patients present to paediatric or adult services, their needs are met.

This article now outlines how a paediatric and adult department in a large teaching hospital have joined forces to set up a seamless adolescent service. This has entailed reorganization of their workstreams to accommodate a clear, well-documented transitional pathway. The authors describe the process and how they jumped, dodged or deconstructed some of the barriers they met. They provide practical pointers to others in similar positions, while acknowledging the financial constraints in health-care services and the different set-ups in other organizations.

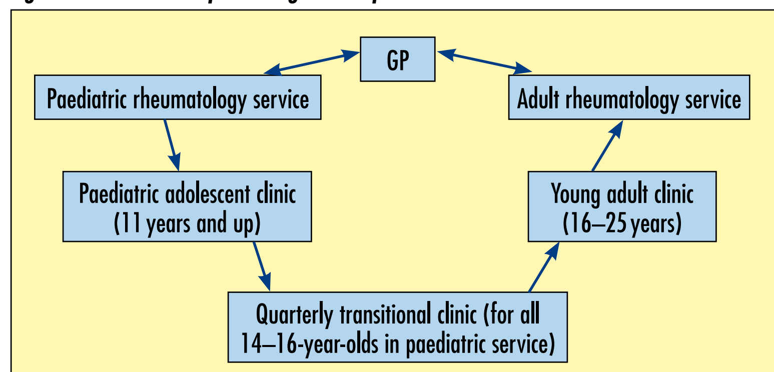
A seamless, MAGICC approach to rheumatology transition

In 2008, Sheffield Rheumatology implemented an adolescent service across two different hospital trusts: Sheffield Children's Hospital and Sheffield Teaching Hospitals. There have been three phases of development.

Phase 1: which clinical pathway?

First, an interested paediatric rheumatologist and adult rheumatologist made informal contact. The adult rheumatologist had completed sub-speciality training in adolescent rheumatology and had a small amount of time (one session) in her job plan to provide adolescent care in the adult service. Both consultants did a literature review of available evidence about how best to 'do' transition and held much debate about what was desirable and practical. Colleagues in different hospitals and disciplines were asked how they provided their services and the authors looked at the sizeable numbers of 10–19-year-olds seen in both hospitals. They shared a clear commitment to a seamless programme to provide uniform, joined-up and high-quality care across both hospital trusts. This work culminated in a skeleton policy document being drawn up to encompass both their aspirations and the possible first steps.

Figure 1. Flow chart representing the components of the authors' service.



The adult service was reorganized to offer first a monthly and then, very quickly because of demand, a fortnightly young people's clinic to see adolescents and young adults aged 16–25 years (*Figure 1*). This provided an obvious place for transitional patients to be transferred to. Then a quarterly joint transitional clinic (to be held in the children's hospital) was suggested to begin to identify the transitional cohort of adolescent patients in the paediatric service. Clinic dates were consistently delayed because of difficulty agreeing funding between the trusts and eventually the team simply agreed dates and ran the clinics as additional activity outside job plans to prove the clinics were both needed and effective.

The clinic was staffed by the paediatric rheumatology multidisciplinary team comprising two clinical nurse specialists, a physiotherapist and an occupational therapist as well as the adult rheumatologist. Patients aged 15 years and up in the paediatric service were seen in this clinic, to meet the adult team on 'home ground' with the aim of transitioning them to the young adult clinic in the adult service when appropriate. Once these clinics were up and running, it was clear that the activity they generated was high and this was an efficient way of doing necessary work. It then became easy to agree a recharging mechanism for the adult hospital to recoup the relatively small cost of the adult doctor's time. This was an important first step in showing this transitional service would simply reorganize existing work and was crucial in engaging managers, whom have been uniformly supportive since.

The final step in the pathway was to identify younger adolescent patients (aged 10 years and up) and see them in a monthly paediatric adolescent clinic to facilitate the transitional process starting young. The adult rheumatologist helps run these clinics as part of the multidisciplinary team and they are part of a governance structure ensuring that she remains skilled in children's rheumatology. The only additional staffing resource has been a small amount of dedicated clinical nurse specialist time from the adult nursing service. The benefit to the adult service of the pathway is in ensuring a steady stream of new patients to the service and as the service grows, the young people's clinic attracts regional and complex referrals.

Phase 2: documentation

The process of setting up the clinic structure and pathway took around 2 years and was phase 1 of the service development. The second phase concentrated on formalizing documentation and revising the policy and path-

way. In the paediatric hospital adolescent clinics dedicated individualized transitional plans were devised for each child and young person (which are paper based). They are a summary version of those widely available (see for example www.dreamteam-uk.org). Annually, from the age of 13 years, these are discussed and completed by young people with clinical nurse specialists in the adolescent clinic in the children's hospital and filed in the medical notes to prompt and guide transitional planning.

Although transition needs to start young, the authors chose to pilot and streamline the documentation in this smaller section of the patient population before rolling out to all adolescents. This was a practical response to the logistics of starting a service from scratch. The process began with a service 'top heavy' with older teenagers needing to transition. In this way the authors have facilitated their transitional process and transfer to adult services. This has evened out the service, releasing time to move on and start individualized transitional plan completion and transitional planning in all patients including those aged 10 years and upwards, as is the eventual aspiration. Children and young people are given an opportunity, and encouraged, to see professionals alone to 'practise' being autonomous and to reinforce the importance of respect and confidentiality. There can be a fine line between engaging young people and seeming to exclude their families and carers in the adolescent clinic. Appointments are set up in the expectation of part of the consultation involving the young person alone and part with their family, carer or friend in the room to try and avoid this feeling of exclusion.

The transitional clinic has evolved such that the initial 'bulge' of 16- and 17-year-olds have been transitioned and now all young people aged 14 years and up are seen once or twice a year. These are not necessarily medical appointments but aim to familiarize the young person and his/her family with the transitional plans, and to recognize where the person is in terms of adolescent development and how the transitional pathway needs to be tailored. These appointments deliver knowledge about health issues and foster skills in self-management of care, with knowledge and skills acquisition being reinforced by the individualized transitional plan process and documentation.

One strength of a clear documentation pathway is that often while young people are seen by nurse specialists to complete individualized transitional plans, parents have an opportunity to discuss ongoing and transfer issues with the medical team (and vice versa). This can be helpful in supporting parents and carers to support their young people in transition. The importance of such parental and family engagement in transition is recognized in the literature (American Academy of Pediatrics et al, 2011) but often neglected in busy clinical settings. The support and engagement mechanisms for families of the young people in transition can be rather ad hoc and the service plans to formalize parental engagement and update transition leaflets to give parents more information and support in the transitional process.

Staff use the HEADSS schema (*Table 4*) to guide consultations (Goldenring and Rosen, 2004) and communication skills and safeguarding training is updated regularly. This ensures that all questions pertinent to adolescent issues are asked (even the more difficult ones about sex and drugs) and acted upon.

Care is transferred around the end of school year 11 to the young people's clinic in the adult hospital. One of the drivers for transfer at 16 years is the local hospital policy where access to paediatric emergency services after 16 years is problematic. In the current era of biological therapy, many patients are on profoundly immunosuppressant treatments. Potentially then, acutely ill 16-year-olds are likely to be admitted to an adult hospital. This is actively discussed with patients and a number elect to have their biologic therapy jointly administered between the paediatric and adult service so they are known to both in the period before transfer. In itself, this joint care has helped those young people's transitional process and broken down some of their worries about transfer. Patient feedback has also been that this kind of tailored arrangement, and the trust it implies that both paediatric and adult services have in each other, has been very important in increasing their confidence in the transitional process in general and transfer in particular.

Transfer of care includes completion of a transfer proforma with detail in domains such as diagnosis, history, treatment, progress, social and educational arrangements. This is completed by the medical team and copied to the patient and the GP. Clear and robust arrangements for transfer of prescribing responsibilities are integral to transfer and the documentation; the service ensures that enough medicines are dispensed by the paediatric team to see the patient through to the adult appointment and a default paediatric appointment stands until transfer is complete as evidenced by copies of two clinic letters received from the adult team. The young adult clinic is staffed by the team already familiar to the young people and their family but in a new, adult hospital setting. With the first appointment letter is sent a 'welcome letter' marking this new phase of care for the young people and confirming the confidentiality of the service. All letters are copied to the young person and confidentiality is a key tenet of the service across both

Table 4. HEADSS questions for guiding adolescent consultations

H	Home?
E	Education/employment (eating)?
A	Activities outside school and home?
D	Drugs (smoking, alcohol, recreational drug use)?
S	Sexuality and sexual health
S	Suicide/spirituality/safety from injury and violence?
And anything else you want to mention?	

adapted from Goldenring and Rosen (2004)

sites. The authors are trying to engage patients' GPs in transition as primary care is often under-used and under-recognized in the process.

Phase 3: patient and parent/carer involvement

The service is just entering phase 3 which is contingent on an understanding that transition is an active process which needs feedback from its service users and clear engagement with primary care. Patients' GPs are under-used in transition and yet may be the one consistent professional known by both the patient and their family. Training days have been set up for local GP colleagues to increase awareness of transition and patients are actively encouraged not to bypass their GPs when seeking routine care; rather they are signposted back to primary care for advice about contraception, intercurrent illness and importantly also for emotional support which has been very helpful for patient and parent or carer alike in the process of transition.

To engage patients, their views have been sought on resources such as the welcome letter, and there is now a patient steering group. This involves mainly patients but also some family members and is facilitated across the service as a whole using an email group. Patients are comfortable (and very honest) in their responses to the questions which have been circulated. In particular they have made helpful comments about clinic timings and research priorities which have shaped the way the service is both provided and assessed (*Table 5*).

In addition the authors have set up a prospective research programme using mixed qualitative and quantitative approaches seeking parent and patient views of the service as a pilot for a larger, multicentre study. The patient steering group was integral in the design of the study and in shaping the research question 'are we getting transition right?' on which this research is predicated. The authors have engaged with regional network colleagues to facilitate regional audit about transition and led this with internal audits of the adolescent service looking at its 'young person friendliness' and the correct completion of documentation. The authors have been surprised at the poor record in documentation in particular, which they believe reflects the pressures of time in clinics and their relative undercapacity and are sure is a limitation experienced by many other services. However, audit data have enabled local discussion of service development and investment with managers and has enabled the building of links with regional centres. This has led to the beginning of a pathway for transition of very complex patients whose care is shared between tertiary and local centres. This emphasizes that transition is never a 'one size fits all' but a service which needs to fit local needs and resources.

Figure 2 gives the experiences of a patient, Holly, and her mum, Sandy, of the service, in their own words.

Table 5. Issues identified by patient steering group and the solutions

Problem	Solution
Morning adolescent clinics are inaccessible as they mean taking time off school or college	Move the clinic to a late afternoon slot; clear reduction in non-attendance
Joint injections can be done with entonox anaesthesia at the children's hospital but not in the adult hospital – this is a barrier in transfer to the adult hospital	Train nurses on the adult day case unit to use entonox so joint injections with entonox anaesthesia can be offered to all adolescents

Figure 2. The experience of the patient and the parent.

The patient – Holly who has juvenile idiopathic arthritis

Age 15 and scared at the thought of attending an adult clinic, I struggled to understand the terminology of what the doctors were saying, I was also scared at the thought of being forgotten about and abandoned. In the transition clinic, Dr McMahon said 'I'm going to sort this', and introduced me to the new team. I remember feeling very scared and 'on trial'. I was introduced to Dr Tattersall and together they set out a plan to get me stable again. As I built a relationship with Dr Tattersall she then transferred me to the adult hospital, and I learned to trust her. She listened, understood and encouraged me to get my life back together, I went from not being able to attend school and feeling abandoned by the adult doctors to looking forward to going to college and learning to drive, living my life again! This clinic supports my whole wellbeing and everyday trials of being a teenager, not just the physical aspect.

The parent – Sandy

Holly didn't follow the normal pattern of juvenile idiopathic arthritis, she had remission and flare up, but sometimes just long grumbling very sensitive unexplained pain. She was sent to the Adult Pain Clinic by her GP, and felt scared about the future: we were left to cope alone. Then one day a miracle happened, we met the adolescent team who took Holly on and treated her condition holistically. Holly is now supported in her juvenile idiopathic arthritis and has developed into a mature, confident young woman, taking responsibility for her own life and treatment. I am proud of the person she has become, with the care and support of the transition team.

Perils and pitfalls in service development

This article is not intended to be too rosy a view of setting up a transitional service. There have been consistent frustrations along the way which have usually been related to resource issues and the challenges of providing a seamless service across different hospital trusts. In starting the original transitional clinics, the authors provided extra clinics to their (already full) job plans in the hope that these would prove both the concept of joint clinics and their utility in delivering a quality service. They were perhaps lucky that managers were persuaded after just less than a year that this was the case, but appreciate that others may not be able to work in this way or have such receptive managers to recognize their value.

An important gap in the service has been a formal pathway to transfer prescribing of medicines such as biologics across trusts. This was not a problem while the service was small, but as numbers have steadily grown patients have identified that processes were not robust as they ran out of medicine or in some cases had two lots of biologics delivered. They challenged the authors to streamline the pathway, which has been done and part of the process is to actively involve patients in planning the prescribing transfer so they are empowered to manage

their own medicines. While the importance of parents and carers in transition has always been recognized, the authors feel they have also been late to involve both them and GPs in the formal transitional processes which has been a gap in the service.

Conclusions

After 3 years, the transitional pathway is now beginning to achieve the authors' initial aspirations for a seamless transitional service. This service development has its origins in an understanding that adolescence is a distinct developmental stage and that adolescent care should be tailored both with that in mind and, ultimately, to empower patients. Best available evidence and expert opinion was used to reorganize and streamline existing work to provide a fluid service which actively involves patients and is both directed by the young people and towards their needs. Sometimes progress has been slow and innovations have had to be implemented in a limited way to prove that they work, before rolling them out. Despite this, as outlined above, the service has continued to move forwards. The team has enjoyed looking after adolescent patients and the guiding principles are truly encapsulated as the MAGICC approach: Moving on in Adolescence; Growing up in Collaboration and Coping. **BJHM**

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KEY POINTS

- Transition happens in adolescence; a time of many physical, emotional and social change for young people.
- Adolescence is a distinct developmental stage which needs to be recognized in the services and care offered to young people.
- Training in adolescent specific issues is patchy and under-resourced.
- Transitional work is not 'new' work but reorganizes existing work streams.
- Engagement of young people and their families in their service is critical.
- Engagement of GPs is an under-used resource in transition.