

# Audit of rheumatology services for adolescents and young adults in the UK

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## Abstract

**Background.** Juvenile idiopathic arthritis (JIA) is associated with significant morbidity in adulthood with at least one third of children continuing to have active inflammatory disease into their adult years and up to 60% of all patients continuing to have some limitation of their activities of daily living. A survey of service provision for these young people in the transition from paediatric to adult rheumatology care was therefore undertaken.

**Methods.** A postal questionnaire was sent to all 92 members of the British Paediatric Rheumatology Group, representing 61 units providing a paediatric rheumatology service in the UK and Ireland.

**Results.** Fifty-five replies were received representing a 60% completion rate of doctors and 84% of units on the mailing list. The majority of respondents were adult rheumatologists ( $n = 36$ , 65%) with 42% of respondents based in teaching hospitals. A median of 24 patients (new and follow-up, range 1–225) were seen in a median of two paediatric rheumatology clinics (range 0–15) per month. Eighteen per cent of units had a dedicated adolescent clinic ( $n = 9$ ) with a median of one clinic per month and a median number of new patients per month of two (range 0–24) and 10 review patients (4–32). All the adolescent clinics involved an adult rheumatologist with five having a paediatrician in clinic and four having access to a paediatrician. The majority of clinics involved a specialist registrar ( $n = 6$ ), a nurse specialist ( $n = 6$ ), an occupational therapist ( $n = 6$ ) and a physiotherapist ( $n = 5$ ). The majority of clinics had flexible entry and exit criteria. In seven clinics there was a standardized process of transfer, first discussed at a median age of 13 yr (range 12–16) but no unit provided literature or organized pre-visits for this process. A demand for patient information resources (e.g. disease and drug information, careers) specifically aimed at adolescents with rheumatic diseases was identified. Generic health issues were only addressed by two clinics. Obstacles to current service provision and ideas for future developments were identified.

**Conclusions.** This survey identifies a heterogeneity of provision of healthcare for adolescents with rheumatic disease and highlights the potential for further research and development.

**KEY WORDS:** Adolescents, Young adults, Juvenile idiopathic arthritis, Transition.

With the improved survival of children with disabilities [1] and increasing prevalence of chronic illness in childhood [2], the transitional management of these young people is viewed as an area of increasing importance and interest. However, adolescent health services in the UK are still at a rudimentary stage of development, with a recent national survey of health authorities reporting that only 9.8% had purchaser specifications for adolescent facilities [3]. Furthermore, two recent

studies of physically disabled young people reported that the quality of medical care declines after transfer to adult services [4, 5]. With the knowledge that there is significant morbidity associated with juvenile idiopathic arthritis (JIA) in adolescence and young adulthood [6–10], the issue of transitional care is particularly pertinent to the growing paediatric rheumatology community in the UK as well as their colleagues running adult services, who provide continuity of care into the adult years.

Transition has been defined as a 'multifaceted, active process that attends to the medical, psychosocial and educational–vocational needs of adolescents as they move from child-oriented to adult-oriented life-style and

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systems' [11]. This movement includes the transition from school to work, from paediatric to adult healthcare systems and from family home to independent living in the community. Different models of transition for young people with chronic illness and disabilities have been described [11–13] and there is emerging evidence that such transitional programmes are associated with positive outcomes, e.g. improved patient satisfaction [14], improved follow-up attendance rates [15], and improved disease control [16].

A key element in the development of transitional care services is knowledge of current practice. Hence, the adolescent subcommittee of the British Paediatric Rheumatology Group (BPRG) conducted a survey amongst members during 1998. The aim was to ascertain current provision of rheumatology services for adolescents and young adults in the transition years.

## Methods

A postal questionnaire was sent to all members of the BPRG during late 1997 and early 1998 addressing current paediatric and adolescent rheumatological practice. For the purpose of this paper, we defined the paediatric age group as under 16 yr and the 'adolescent' age group as 16–25 yr to reflect the division of services in the UK. A second postal reminder was sent to first wave non-responders. The responses were not anonymized. The questionnaires were analysed using Microsoft Excel software.

## Results

At the time of the survey, there were 92 doctors practising paediatric rheumatology in the UK and Ireland who were members of the BPRG and who represented 61 hospital units. Fifty-five replies were received (completion rate of 60%). However, these 55 respondents represented 51 units and there were 14 non-respondents from 10 units for which there is no information.

The majority of respondents were of consultant status ( $n = 49$ , 89%) and the majority were adult rheumatologists ( $n = 36$ , 65%) (Table 1). Twenty-three (42%) of these physicians were based in teaching hospitals serving local and regional populations and 30 (54%) were based in district general hospitals serving local populations and two (4%) had dual commitments.

TABLE 1. Characteristics of respondents

	Consultant	Specialist registrar
Adult rheumatologist	36	2
Paediatrician	5	0
Paediatric rheumatologist	6	4
Paediatrician who sees adult patients with adult rheumatologist	1	0
Data unavailable	1	0
Total	49	6

## Current paediatric rheumatology practice of respondents

The following data represent 51 paediatric rheumatology units in the UK and Ireland. The median number of fixed paediatric rheumatology sessions per consultant was two per month (range 0–40) with the median number of paediatric rheumatology out-patient clinics being two per month (range 0–15). There was a median of six new patients (range 0–40) and 14 (range 0–200) review patients were seen monthly, i.e. a median of 23.5 (range 1–225) seen per month. The majority of respondents ( $n = 48$ , 87%) had access to paediatric beds. Dedicated paediatric rheumatology beds were available in only four units.

## Current adolescent rheumatology practice

Of the 51 units who responded, nine had a dedicated adolescent clinic (18%) with two other units in the process of planning one (Table 2). Clinic environments were paediatric ( $n = 4$ ) and adult ( $n = 5$ ). Eight had a separate waiting area for adolescent patients. In the respondents' opinion, all were 'user friendly' to young adults but only three to children.

In seven clinics there was a 'standardized process' (not defined in questionnaire) to transfer patients to the adolescent clinic from the paediatric clinic. Transfer was initially discussed at a median age of 13 yr (range 12–16), but no unit provided literature or organized pre-visits for this transfer process. In five clinics patients were routinely seen separately from parents. This concept was introduced at 12–14 yr in three clinics and prior to entry at 16 yr in the remaining two clinics.

Table 3 details the personnel currently involved in the nine adolescent rheumatology clinics identified by this survey. Many of the existing adolescent clinics had formal contact and access to services including Young Arthritis Care ( $n = 6$ ), careers advisors ( $n = 5$ ), disabled employment advisors ( $n = 5$ ), Lady Hoare Trust social workers ( $n = 4$ ) and psychology ( $n = 5$ ).

A variety of specific resources was available in the

TABLE 2. Current adolescent rheumatology practice in the UK

Dedicated adolescent rheumatology clinics	
Established	9 (18% of responding units)
At planning stage	2
Median number of adolescent sessions per month (range)	1 (every 3 months to 5)
Median number of patients seen per month	
New patients	2 (0–24) <sup>a</sup>
Review patients	10 (4–32) <sup>b</sup>
Flexible entry and exit criteria (number of clinics)	8
Median age for entry to adolescent clinic (yr)	16 (12–17)
Age range at exit from adolescent clinic (yr)	18–25 <sup>c</sup>
Standardized process for transfer (number of clinics)	7

<sup>a</sup>Data unknown for two centres.

<sup>b</sup>Data unknown for one centre.

<sup>c</sup>Data available from four centres.

TABLE 3. Personnel involved in current adolescent rheumatology clinics

	Number of adolescent rheumatology clinics ( <i>n</i> = 9)
Consultant rheumatologists ± consultant paediatricians	5
Other consultants	
Orthopaedic	1
Rehabilitation	1
Metabolic bone	1
Ophthalmologist	1
Specialist registrar in rheumatology or paediatrics	6
Clinical nurse specialists	7
Occupational therapists	6
Physiotherapists	5

nine adolescent clinics, which are listed in Table 4. In units (*n* = 3) with adolescent beds, these were either on a dedicated ward or a dedicated bay on the ward. In units where there were no dedicated adolescent in-patient beds, some reported the availability of teenage areas and youth workers.

A young disability team (or equivalent) was involved in three adolescent clinics with formal liaison planned in one other. Seven other units, however, which had no formal adolescent service, used a young adult disability team or equivalent. Patient involvement was encouraged in some clinics through various practices such as patient-held drug monitoring forms and sending copies of clinic letters to the patient.

Amongst the respondents with adolescent clinics, medical personnel felt the clinics were worthwhile and enhanced patient care with free text comments including: (They) 'encourage patient self-responsibility from a young age and the development of confidence and assertiveness'. '(They) facilitate a holistic approach with educational transitional plans for those who need them'; '(They) provided opportunity to explore the adolescent's concerns separate from the parent(s)'. In some clinics, the continuity of care provided by the same rheumatolo-

TABLE 4. Available adolescent rheumatology resources

Resource	Number of adolescent rheumatology clinics ( <i>n</i> = 9)
Patient information for adolescents re: disease and treatment	4
Patient information re: generic health issues	2
Disability allowance information	6
Patient education sessions	2
Access to rehabilitation services	5
Dedicated adolescent hydrotherapy sessions	5
Dedicated adolescent aerobic sessions	1
Residential independence breaks	1
Patient-parent support groups	1
Social events	1
Educational events	1

gist in the paediatric, adolescent and adult clinics was highlighted as a strength.

In units where there was no dedicated clinic, current provision for adolescent patients was varied and included shared care between paediatricians and adult rheumatologists in a paediatric adolescent unit and the support of a nurse specialist.

The survey invited suggestions to improve the development of adolescent rheumatology in the UK. There were 31 respondents whose comments are summarized in Table 5. Clearly there is enthusiasm to expand the current level of services and especially to increase patient educational resources and inter-agency liaisons.

The survey also invited respondents to detail perceived obstacles (if any) to the development of adolescent rheumatology in the UK. These are summarized in Table 6.

## Discussion

This survey was the first national survey of adolescent rheumatology services in the UK and identifies the heterogeneity which exists in the provision of healthcare for adolescents with rheumatic disease and highlights the perceived potential for further service development. Despite an estimated 19 656 children and adolescents seen every year in 61 paediatric rheumatology clinics, this survey revealed that only nine units (18%) had a designated adolescent clinic.

TABLE 5. Suggestions for future adolescent rheumatology service provision in the UK

	No. of responses
Service provision	
Development of transition clinics (if none available at present)	7
Development of transition procedure	1
After school clinics	1
City-wide venture of amalgamation of clinics	2
Appointment of additional staff (not specified)	2
Full-time adolescent rheumatologist	1
Specialist nurse	1
Physiotherapist	1
Outreach clinic support from regional centres	3
Dedicated adolescent physiotherapy sessions	1
Integration with local disability services	2
Increased liaison	
with district paediatricians	2
with adult rheumatologists	1
between therapists	1
Use of standard diagnostic information, outcome measures	2
Education	
Patient	4
Information packs	
Education for parents	
Increase availability of careers and disability benefit advice	
Patient-held records/drug monitoring	
Doctor	
Education days	2

TABLE 6. Obstacles to the development of adolescent rheumatology

Obstacles	No. of responses
Limited demand—too few patients	2
Insufficient adult rheumatology team support	4
Lack of adolescent in-patient beds	1
Lack of enthusiasm and priority from certain team members	1
Availability of full team at time of clinic	2
Limited availability of patient information dedicated to adolescence	4
Clinic space	2
Adolescent clinic setting	2
Time constraints	5
Timetable matching	1
Split-site working	1
Funding	5

### *The need for adolescent rheumatology services*

The outcome of JIA into adulthood supports the need for continuity for care in the transitional period. At least one third of children with JIA continue to have active inflammatory disease into their adult years [6–8] and up to 60% of all patients continue to have some limitation of their activities of daily living [6, 8–10]. Furthermore, it has been shown that for many young people in the UK with chronic arthritis, unemployment is common and does not correlate with educational achievement or level of disability [8, 17].

Some critics would say that the numbers of patients do not justify the development of adolescent rheumatology. It was therefore interesting that whereas several respondents explained their lack of a dedicated adolescent clinic as due to limited demand, others reported the small size of the clinic as a strength in view of the transition needs of this patient population. Data from the BPRG diagnostic register show that 27.3% of incident cases of JIA develop their disease between the ages of 10 and 16 yr (P. Woo, personal communication). In a national healthcare need assessment, the presentation of several musculoskeletal diseases in the 15–24 yr old age group was shown to be not uncommon [18]. Although for most patients the problems are self-limiting, for many the course becomes chronic and this has a major impact on resource planning for this age group. In summary, therefore, the development of transitional care services is justified both in our ability to respond and in terms of numbers of young people.

### *Transition process*

The aims of transition are:

- (i) to provide co-ordinated, uninterrupted healthcare which is age-appropriate, developmentally appropriate and comprehensive;
- (ii) to promote skills in communication, decision-making, assertiveness, self-care; and
- (iii) to enhance sense of control and independence of healthcare.

Transition must be seen in the context of adolescent

development where the inter-dependent major tasks of adolescence are to consolidate his/her identity, to establish relationships outside the family, to achieve independence from parents and to find a vocation [19].

Acknowledging the above, the adolescent rheumatology clinic aims to facilitate the transition from the traditional paternalistic paediatric care to the typical adult general rheumatology clinic format where the patient is expected to take on more responsibility for their own healthcare. The process of transition is not clearly defined, although several different models have been proposed [11, 15]. Key elements of an effective transition programme in the UK have been proposed [3]

- (i) A policy on timing of transition and transfer.
- (ii) A preparation period and education programme.
- (iii) A co-ordinated transfer process.
- (iv) Administrative support.
- (v) Primary care involvement.

There is considerable variation in physical, cognitive and psychosocial maturation of the developing adolescent and the effect of chronic arthritis can have considerable adverse impact, e.g. growth retardation, delayed puberty and cushingoid side-effects of treatment. Therefore, the age at entry to the transition process must be decided on an individual basis and this is exemplified by the flexible entry and exit criteria shown in the nine adolescent clinics identified in the survey.

White stresses the importance that the process should begin the day of diagnosis for children with disabilities, their families and the providers [11]. 'The process of developing a transition plan reaffirms the ability, not disability, of the adolescent' [11]. A survey of service providers in the rehabilitation, education and medical care of children in the USA showed that not planning for transition was second only to financing as the most common reason for failure of moving successfully into an adult-oriented system [20]. An unsuccessful transition process may be due to fear of the unknown and failure to recognize that there is a need to move on into adult-oriented care, and serves only to reinforce the negative image of the young person not becoming an adult and that they are different from their non-disabled peers. If anticipated as described, however, it serves as an important positive message to the young person and their family. Preparatory literature and pre-organized visits to the transition and/or adult clinic may be useful but were not provided by any of the units in this survey.

Patient empowerment, including education, communication and self-advocacy skills, is integral to successful transition and is a key area in current National Health Service policy. One of the (many) objectives of transition in adolescent healthcare is for the young person to take over gradually the responsibility for their therapy, i.e. to become their own advocate. An individualized goal-setting yet flexible policy is appropriate. Plans for self-medication, self-injection of subcutaneous methotrexate, patient-held monitoring forms, provision of personal copies of clinic letters for the adolescent themselves are current examples identified from the survey.

It is important that the transition plans must address the evolving role of the parent(s) who should be actively involved in the transition process whilst encouraging independence for the patient. This must be individualized to the family, be flexible and acknowledge the difficulties faced by parents on whom the young person has hitherto been dependent. In this survey, only five adolescent clinics described a policy of patient consultations separate from the parents. Details regarding parallel transition programmes for parents were not specifically requested in the current survey, although one clinic reported a patient/parent support group.

#### *Paediatric–adult rheumatology interface*

Many of the studies of outcome in JIA within the UK have been based in tertiary referral centres and therefore prone to selection bias. Furthermore, many paediatric patients have been 'lost' to adult clinics or discharged to community care from where they may be later referred with complications due to their disease. A co-ordinated approach in the transitional period is therefore required to provide continuity of care for the patient and facilitate prospective research. It was interesting to note, therefore, that 65% of respondents to this survey were adult rheumatology consultants and all adolescent clinics had an adult rheumatologist. Conversely, four respondents identified the lack of adult rheumatology support as an obstacle to the development of adolescent rheumatology service provision in their locality. The significant involvement of adult rheumatologists both in the adolescent rheumatology clinics identified and in the BPRG as a whole will aid the future development of such services in the UK. Adult rheumatologists, however, may need further training and must liaise closely with adolescent health teams and paediatricians. The interested adult rheumatologist with experience in paediatric rheumatology may facilitate the transition process further in provision of young adult clinics (16–25 yr), allowing continuity of care from the paediatric to adult healthcare systems and facilitating prospective outcome research. This need was recently identified by one of the authors in Newcastle upon Tyne where a paediatric rheumatology clinic had existed since 1996. In the first 18 months of this young adult rheumatology clinic, referrals have grown steadily and currently include 190 patients with JIA.

#### *Resource provision*

This survey identified a demand for patient information resources specifically aimed at adolescents, an area ideally suited for collaboration between the BPRG, Arthritis Research Campaign and Young Arthritis Care. There is a paucity of literature aimed at the adolescent with arthritis, a point highlighted at the recent Arthritis Research Campaign 'Education Week 1999'. Recent patient surveys demonstrate support for separate adolescent clinics and demand for more information (especially on JIA, medication, orthopaedic surgery as well as relationships and benefits) [21] (B. Beresford, personal communication). Lang *et al.* reported a 'needs assess-

ment' in order to develop an effective transition programme [22]. The need most frequently ranked as important or very important by the adolescents was to be involved in decision-making about their disease (80%). The needs ranking next highest were: education about new developments in the area of their disease (72%), understanding medication side-effects (70%) and learning how to manage pain (70%) [22]. Similar needs assessment processes should be considered prior to the development of new transition services in the UK. Preliminary results from a national study of adolescents with chronic illness in the UK (including JIA) report that adolescents would also like to choose the gender of the doctor (if possible), that the doctor be interested and would respect them, give them time and talk direct to them, giving them an opportunity to ask questions (B. Beresford, personal communication).

Provision of resources regarding other health issues, e.g. drug misuse, alcohol, contraception, pregnancy, etc. should also be considered in any adolescent healthcare service [23] and were only addressed by two of the clinics identified. Issues such as alcohol and contraception/pregnancy are important areas for general health and also impact upon the use and monitoring of disease-modifying therapy such as methotrexate. Carrol *et al.* reported that adolescents with chronic illnesses reported more age-related concerns (e.g. acne, alcohol/drugs, contraception, sexual health) than their peers [24]. Interestingly, in the Canadian study, one of the areas of greatest discrepancy was the need for education about drugs/smoking/alcohol, endorsed by 97% of parents compared with 56% of adolescents [22]. From this it could be postulated that either the adolescents are truly naive or actually know a lot more than they are letting on!

Information and advice regarding careers was another area of need identified by this current survey. Preliminary results from a national study of adolescents with chronic illness (including JIA) report that adolescents identify a need for early and appropriate career counselling, mentoring, and information about benefits (B. Beresford, personal communication). The trend towards unemployment starts in adolescence. Successful career development in young people with chronic illnesses and/or disabilities requires consideration of not only educational achievement but also such issues as, e.g. prior work experience; psychological factors such as self-esteem; expectations of both the young person, their family but also teachers, health professionals; knowledge of availability of resources, e.g. career services; and societal attitudes towards chronic illness and/or disability [25].

#### *Inter-agency liaison*

Inter-agency liaison is important in the transition process but may be disadvantaged by the hospital-oriented care of many of the paediatric and adolescent rheumatology clinics. At least half the adolescent clinics had formal access to key agencies including Young Arthritis Care, Lady Hoare Trust, disability employment advisors, etc.

A community-based generic transition co-ordination model has been recommended to be more useful in this regard [26] and is well established in Leeds. It is noteworthy that this survey identified some units ( $n = 6$ ) where although there was no formal adolescent service, there was use of a young disability team in the locality. Determining which transition model is best may not be the same for all areas or indeed for all adolescents and further study is required.

### Summary and recommendations

The ultimate aim of any transition programme is to enable children to lead successful and meaningful lives as adults with (or without) a disability. The high cost of failing to address the needs of these young people has previously been recognized [27]. This survey has identified a heterogeneity of service provision for adolescents with rheumatic disease and highlighted specific areas for further exploration and development at a local and national level which included:

- (i) transition policy planning (e.g. entry and exit criteria, independent consultations for adolescents, etc.);
- (ii) development of educational resources directed to the adolescent age group;
- (iii) inter-agency liaison, e.g. with young adult disability teams etc.

The literature highlights the need for transition planning [20, 27, 28]. The 'ideal' transition service has not yet been identified and further research is required and must be evaluated in terms of patient outcomes (e.g. quality of life, employment) as well as cost effectiveness. The morbidity of JIA in adulthood [6–10] supports the development of multidisciplinary, transitional services in every paediatric rheumatology centre. The BPRG are in the position to take the lead in such research and service development and a multicentre study of transitional care for adolescents with JIA in the UK is currently in preparation. This in turn can be compared with a current study comparing outcomes of focused young adult team provision in two cities in the UK with the usual *ad hoc* services (M.A. Chamberlain, personal communication). As health professionals and members of multidisciplinary teams involved in the care of young people with rheumatic disease, we can act as catalysts, planners, co-ordinators and researchers in the transition process. To quote one respondent, 'We could do better and should do better'.

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