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**EULAR / PReS standards and recommendations for the transitional care of young people with juvenile onset rheumatic diseases**

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Complete List of Authors:	<p>Foster, Helen; Newcastle University, Institute of Cellular Medicine (Rheumatology)          Minden, Kirsten; Children´s university hospital Charité, Campus Virchow, SPZ; German Rheumatism Research Centre, Epidemiology Unit          Clemente, Daniel; Hospital Infantil Universitario "Niño Jesús", Paediatric Rheumatology Unit          Leon, Leticia; Hospital Clínico San Carlos, Instituto de Investigación Sanitaria del Hospital Clínico San Carlos (IDISSC); Universidad Camilo José Cela, Madrid, Health Sciences          McDonagh, Janet; University of Manchester, Centre for Musculoskeletal Research          Kamphuis, S; Erasmus MC - Sophia, Immunology and Infectiology          Berggren, Karin; Karolinska Universitetssjukhuset          van Pelt, Philomine; Erasmus MC Sophia Children's Hospital Rotterdam, Department of Paediatrics/Paediatric Rheumatology          Wouters, Carine; University Hospital Gasthuisberg, Pediatric Immunology          Waite-Jones, Jennifer; University of Leeds, School of Healthcare          Tattersall, Rachel; University of Sheffield, School of Health and Related Research          Wyllie, Ruth; Newcastle Upon Tyne Hospitals NHS Foundation Trust, Paediatric Rheumatology          Stones, Simon          Martini, Alberto; Università degli Studi di Genova Scuola di Scienze Mediche e Farmaceutiche, Pediatria II          Constantin, Tamas ; Semmelweis Egyetem, Department of Pediatrics          Schalm, Susanne ; Transitionssprechstunde am Dr. von Haunerschen Kinderspital, Ludwig-Maximilians-Universität München          Fidanci, Berna; Gulhane Military Medical Academy, School of Nursing, Ankara, Turkey.          Erer, Burak; Istanbul University, Istanbul Faculty of Medicine, Department of Internal Medicine, Division of Rheumatology          Demirkaya, Erkan; Gulhane Military Medical Faculty, Pediatric Rheumatology Unit, FMF Arthritis Vasculitis and Orphan Disease Research in pediatric rheumatology (FAVOR), Etlik, Ankara 06018, Turkey          Özen, Seza; Hacettepe University Medical Faculty, Pediatric Rheumatology          Carmona, Loreto; Instituto de Salud Musculoesquelética,</p>

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**EULAR / PReS standards and recommendations for the transitional care of young people  
with juvenile onset rheumatic diseases**

Authors

Helen E Foster\*

Kirsten Minden\*

Daniel Clemente

Leticia Leon

Janet E McDonagh

Sylvia Kamphuis

Karin Berggren

Philomine van Pelt

Carine Wouters

Jennifer Waite-Jones

Rachel Tattersall

Ruth Wyllie

Simon R Stones

Alberto Martini

Tamas Constantin

Susanne Schalm

Berna Fidanci

Burak Erer

Erkan Dermikaya

Seza Ozen

Loreto Carmona

\* Drs Foster and Minden contributed equally.

## ABSTRACT

**Aims.** To develop standards and recommendations for transitional care for young people (YP) with juvenile onset rheumatic and musculoskeletal diseases (jRMD).

**Methods.** The consensus process involved the following: 1) Establishing an international expert panel to include patients and representatives from multidisciplinary teams in adult and paediatric rheumatology 2) A systematic review of published models of transitional care in jRMDs, potential standards and recommendations, strategies for implementation and tools to evaluate services and outcomes; 3) Setting the framework, developing the process map and generating a first draft of standards and recommendations; 4) Further iteration of recommendations; 5) Establishing consensus recommendations with Delphi methodology; and 6) Establishing standards and quality indicators.

**Results.** The final consensus derived 12 specific recommendations for YP with jRMD focused on transitional care. These included: high quality, multidisciplinary care starting in early adolescence; the integral role of a transition coordinator; transition policies and protocols; efficient communications; transfer documentation; an open electronic-based platform to access resources; appropriate training for paediatric and adult health care teams; secure funding to continue treatments and services into adult rheumatology; and the need for increased evidence to inform best practice.

**Conclusions.** These consensus-based recommendations inform strategies to reach optimal outcomes in transitional care for YP with jRMD based on available evidence and expert opinion. They need to be implemented in the context of individual countries, health care systems and regulatory frameworks.

## INTRODUCTION

**Transitional care**, as defined by the Society for Adolescent Medicine, is "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems".[1] Transition does not only focus on the administrative event of transfer of care between paediatric and adult providers; transition encompasses the process by which young people (YP) acquire skills and access resources to ensure that their physical, psychosocial, educational and vocational needs are met during transition to adulthood.[2] Adolescence and young adulthood reflect an important and unique developmental period for all YP who need education, support, guidance and planning to prepare them to be appropriately responsible and accountable for their own health and well-being as adults.[3] The same principle applies to YP with chronic illnesses (including juvenile-onset rheumatic and musculoskeletal diseases [jRMDs]) who need to acquire additional skills to independently manage their chronic illness. The case of need for transition is well described and transitional care aims to provide support and guidance so that YP can acquire the necessary skills and knowledge required to be independent, empowered and responsible adults.[4-7]

The course of jRMDs often continues into adulthood; according to population-based inception cohort studies approximately half of YP with jRMDs enter adulthood with active disease, or develop flares of disease as adults. Many YP require ongoing and often long term treatment with complex immunosuppressive regimens.[8-10] Disease related sequelae are still observed, although with modern approaches to management, many YP are transferring to adult care in clinical remission albeit on medication.[11-13] All YP with jRMDs are, in principle, at significant risk of disability, early morbidity and limitations in participation later in life.[14, 15] These YP need continuous and developmentally appropriate care during and beyond adolescence to ensure optimal functioning in adulthood.

However, the literature informs us that currently up to half of the YP do not make a successful transfer to adult rheumatology and are therefore at particular risk of unfavourable outcomes.[16-18]

The importance of transitional care in YP with jRMD has been increasingly acknowledged.[19, 20]

There is evidence regarding 'best practice' for transitional care, with emphasis on a holistic 'life course' approach to care.[21-23] Several healthcare institutions, specialties, and disease specific subgroups have developed and implemented transition programmes.[24-34] However, there is lack of clarity regarding the impact of transition programme on outcomes, and indeed, variance in what the outcomes should be.[35-40] A first consensus-based proposal regarding outcome indicators for successful health care transition was recently made by an international group of interdisciplinary health care professionals, patients and their families.[41] With rheumatology, there are significant gaps in current delivery of transition services and these include the unmet training needs for health

care professionals in adolescent health and transitional care (resulting in lack of understanding and appreciation of the needs of YP), lack of transition readiness of YP (and/or of their parents/carers), and lack of robust quality indicators or cost-effective strategies.[2, 36, 42-48]

Despite the limitations of the existing programmes, the gaps in knowledge and the paucity of resources, there is nonetheless commitment within the rheumatology communities (both adult and paediatric), to improve existing transitional care services. There is a strong desire for rheumatology-specific guidelines for transition [48] and for these to be implemented across paediatric, adolescent and adult rheumatology health care settings.

### **Objectives, scope, users and overarching principles**

The objective of the present initiative was to develop recommendations and standards for transitional care for YP with jRMDs, spanning ages from early adolescence (defined as 10 to 13 years), mid adolescence (14-16 years), late adolescence (17 to 19 years) to young adulthood (20 to 24 years).[49, 50] These recommendations and standards are to be used to guide service development, benchmark the quality of transition services and be used by patient organisations to enhance patient expectations of care. We acknowledge that their implementation into clinical practice will be challenging and likely to be facilitated by stratification into ‘essential’ and ‘ideal’ components—**essential** defined as the *minimum* standards below which care would be deemed unacceptable and **ideal** being the standard that is regarded as excellent “optimal” care.

The purpose of these recommendations and standards is to increase the profile of transition, optimise delivery of transitional care and improve patient experience within rheumatology across European countries. Specifically, the objectives are:

- to ensure youth friendly and developmentally appropriate care
- to improve physical, psychological, social, vocational and illness-related outcomes of YP with jRMDs
- to facilitate continuity of care within adult rheumatology
- to promote evidence based practice in transitional care
- to facilitate clinical networks of health care professionals (paediatric and adult) who are engaged, interested and trained in the care of YP

The scope of these recommendations and standards refers to all persons involved in the care of YP with jRMDs that continue into adulthood including, but not restricted to, those in Table 1.

Although these recommendations and standards are related to the specific needs of YP with jRMDs, our expert panel endorse the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine consensus statement on health care transitions for YP with special health care needs,[51, 52] position papers of the Society for Adolescent Medicine,[1, 53-55] the Canadian Paediatric Society,[56] the Royal Australasian College of Physicians,[57] and the WHO definition of adolescent-friendly health services.[58, 59] In addition, we emphasise key components integral to these recommendations and standards, namely the importance of a YP focus, multidisciplinary approach with equity of access, quality of care and flexibility; the latter acknowledging both the heterogeneity of YP development and potential impact of chronic illness.

### **METHODS**

The consensus process underwent the following stages: 1) Establishing an international expert panel to include patients and representatives from multidisciplinary teams in adult and paediatric rheumatology; 2) A systematic literature review; 3) Setting the framework, developing the process map and generating a first draft of standards and recommendations; 4) Further iteration of recommendations; 5) Developing consensus recommendations with Delphi methodology; and 6) Establishing standards and quality indicators, as suggested by the EULAR Standard Operating Procedures.[60]

The project convenors (HF, KM, LC) liaised to appoint clinical fellows (DC, LL) to work on the project. They then convened an expert multidisciplinary panel from adult and paediatric rheumatology across Europe (doctors and allied health professionals with interest in transitional care) and patient representatives (YP with jRMDs invited from existing patient groups). The aim was for the panel to reflect the diversity of Europe (namely geography, health care systems and cultures).

A systematic literature review of existing models of transitional care in jRMD was performed, with emphasis on potential recommendations, standards, strategies for implementation and tools to evaluate services and outcomes.[61]

The first 'face-to-face' meeting of the expert panel discussed results of the systematic review and agreed the following:

- i) purpose of the project, timelines, roles and planned outputs
- ii) the 'process map' of transitional care using MindManager™ software



- iii) a draft proposal of recommendations and standards relating to different elements of the process map; the proposed list was circulated after the meeting by email to the expert group and further feedback requested.

A second 'face-to-face' meeting further refined the recommendations and standards based on feedback from the group. Appropriate quality indicators were also suggested for each recommendation and standard.

The recommendations and standards were then listed as statements. A wider audience of a total of 195 adult and paediatric rheumatology clinicians (doctors and allied health professionals) were then invited to take part in an e-survey and give opinion of their level of agreement with each statement. The e-survey was disseminated through email lists held by professional groups (such as PReS, EULAR and rheumatology societies in different countries). All responses were anonymised. Participants were asked for their level of agreement with each statement (using a 10 point Likert scale, with 0 = No agreement through to 10= Total agreement) and a ranking exercise to identify "minimal" and "optimal" standards for each recommendation. The target number of respondents for the e-survey was 100 and the level of agreement set at 80% for acceptance (lower levels were to be then discussed by the expert panel, with further iterations of the statements proposed and then a second e-survey, if needed, to be disseminated). Once agreement was reached, the methodologist (LC), together with the clinical fellows (DC, LL), graded the level of evidence for each recommendation based on the Oxford Levels of Evidence, 2011 (available at <http://www.cebm.net/index.aspx?o=5653>) and assigned relevant quality indicators where appropriate.

### **RESULTS – The recommendations and standards**

The recommendations and standards, reported as "minimal/essential" and "ideal/optimal" levels of care and quality indicators are listed below; they are also presented in table format with the level of evidence and agreement reached (Table 2).

- 1. YP with jRMDs should have access to high quality, coordinated transitional care, delivered through partnership with health care professionals, YP and their families, to address their needs on an individual basis.**

High quality care means holistic care (which covers medical, psychosocial, educational and vocational aspects; see table 3) with a multidisciplinary approach and is based upon regular assessments of the disease status in the context of developmental stage, life events and personal aspirations of YP. This care needs to be 'future-focussed', albeit not limited to young adulthood, in order to ensure optimal well-being.[19, 23]

Ideal- Provision of a broad set of health care services led by providers who have specialist knowledge about JRDs and adolescent health; Essential: care providers who refer to other agencies and services who can appropriately assist with transition issues.

**2. The transition process should start as early as possible; in early adolescence or directly after the diagnosis in adolescent-onset disease.**

Specifically for childhood onset diseases, the transition process should start by early adolescence (11 years) (Ideal) or 14 years at the latest (Essential) in order to allow the development of the necessary self-care skills and optimise educational and vocational outcomes.[62, 63] For YP who are diagnosed over the age of 14 years the transition process should start at the time of diagnosis with the skills and support for transition built up over time. The transition process or joint care programs should enclose early adulthood, because young adults continue to have difficulties making effective linkages with adult care. Brain development continues and risk behaviours remain and may increase in the third decade, which have to be considered by proactive and preventive care.[64]

**3. There must be 'direct' communication between the key participants (and as a minimum, to include the YP, parent/carer, and a member of each of the paediatric and adult rheumatologist teams) during the process of transition. Before and after the actual transfer there should be 'direct' contacts between paediatric and adult rheumatologist teams.**

A network of adult rheumatologists interested, engaged with and trained in adolescent rheumatology, must be identified and known to the paediatric rheumatology team. The network should work within agreed pathways to facilitate transition and expedite early, active planning of transition. Ideally, there should be a combined meeting between the young person and his or her family, the paediatric and adult health care provider.[65-67] As a minimum, there should be at least two 'direct' contacts by telephone or email between the paediatric and adult rheumatology team (and documented in a written communication); one before and one after the transfer. Copies of written communications are to be made available to YP and families. Online supplementary table contains suggested guidelines regarding the content and format of communications at different stages of transitional care.

**4. Individual transition processes and progress should be carefully documented in the medical records and planned with YP and their families.**

Documentation should support the YP engagement and self-management skills, resilience and readiness for transfer.[68-72] This documentation should be tailored to local services, shared with the YP, and contribute to the medical summary. The inclusion of sensitive or confidential information (e.g. abortion, mental health problems) should be discussed with the YP. Ideally, there is a specific written individual transition plan,[26] which can be derived from a transition plan or passport example, such as

<http://www.uhs.nhs.uk/Media/Controlleddocuments/Patientinformation/Childhealth/Ready-Steady-Go-Transition-plan.pdf>. [21] As a minimum, the existence of a transitional care process has to be

documented in the medical records. Additional resources are listed in Supplementary material.

**5. Every rheumatology service and clinical network—paediatric and adult—must have a written, agreed, and regularly updated transition policy.**

Policies and protocols should be agreed with all major stakeholders, including YP, families and all health care professionals and as equal partners; [27, 33, 61] it is important to stress the need to include all specialists (and not just in rheumatology) and primary care physician(s) who are involved in the clinical care of YP with jRMD [28] Hospital or institutional managers will have to agree to these policies to facilitate appropriate resources to support their implementation within the clinical departments. As a minimum, there must be a transition policy and the documents should be updated at least every five years. It is acknowledged that there is need for flexibility of the arrangements in transition policy and care pathways at a network level.

**6. There should be clear written description of the multidisciplinary team (MDT) involved in transitional care, locally and in the clinical network. The MDT should include a designated transition coordinator.**

The team for transitional care should reflect the multidisciplinary approach, i.e. doctors and other health professionals, such as nurses, physical therapists, psychologists, occupational therapists (OT), and youth or social workers. [28, 73, 74] It is recognised that certain roles within transition are likely to be addressed by different members of the MDT. [75] In addition, it is acknowledged that the composition of MDTs is variable and that some members may have more than one role. Ideally, there is personal continuity in the health professionals within the MDT providing care. [43] This provision of roles and services may be shared with other specialist services and not devoted solely to jRMDs. There should be a nominated and identified member of the MDT who is responsible as transition coordinator (Essential). This person can be a nurse or other health professional and should liaise between adult and paediatric teams to ensure the coordination of care, facilitation of communication and implementation of the transitional care plan including transfer. [61]

**7. Transition services must be YP focused, be developmentally appropriate and address the complexity of YP development.**

Components of YP focused care need to include: accessibility to specialised health care, staff attitudes, communication, medical competency, guideline-driven care, age appropriate environments, and youth involvement in health care. [76] Ideally, there should be a care facility that is truly adolescent-friendly staffed by professionals with expertise in adolescent care. The care should be organised to minimise

the frequency of appointments and interruption to the daily life of YP. The aim of the consultations with the MDT is to enable YP to take lead role instead of the parent / carer(s), whilst also supporting the parent/carer(s) in their changing roles.[43, 77, 78]

YP with jRMDs should have access to peer discussion and support through advisory group(s) and charity networks. Signposting to such groups and networks is the responsibility of the clinic where the YP attends. As a minimum, transitional care services should be led by staff with expertise and training in adolescent and young adult healthcare.

### **8. There must be a transfer document.**

The format and content of transfer documents should be agreed by paediatric and adult teams and with patient input where possible. The transfer document should include, as a minimum, a medical summary with the diagnosis, any comorbidities, vaccinations, any complications of disease or treatments, the professionals involved in care, current and previous treatments (with reasons for changing treatments and any adverse events). Ideally, it should also include: i) Psychosocial aspects and educational / vocational status at the time of transfer, and ii) A report on self-management skills, to include readiness for transfer and procedural pain management strategies (e.g. for joint injections with or without general anaesthesia).[79]

This transfer document may also include contributions from members of the MDT as appropriate and if relevant. Any confidential information or sensitive information to be included in the transfer document should be discussed with the YP; if needed, this should be included in a separate letter to the adult rheumatologist and be written ahead of the first consultation with adult rheumatology. Copies of the transfer document should be available to YP themselves in an easy read format if appropriate, and to all health care providers, including primary care, involved in the young person's care.[80]

### **9. Health care teams involved in transition and adolescent-young adult care must have appropriate training in generic adolescent health and childhood onset RMD.**

All members of the clinical MDT (from adult and paediatric rheumatology) engaged in transition are to have training on adolescent health and the process of transition.[46, 48] As a minimum, the key training components to be covered are: 1) jRMDs (presentation in childhood, knowledge and approaches to management), 2) Adolescence health and the impact on jRMDs, 3) Skills and knowledge to address emotional, mental health and social issues, 4) Promotion of healthy lifestyle and generic health issues, 5) Promotion of self-management and shared decision making, 6) Communication skills with young people and their parent/carer(s).

These skills and knowledge can be acquired through different ways of learning (e.g. to include clinical experience, e-learning, and practical workshops) and should be a component of continuous professional development. There are many courses and e-learning opportunities available, such as the EULAR/PReS On-line Course in Paediatric Rheumatology ([www.eular.org/edu\\_online\\_course\\_paediatric.cfm](http://www.eular.org/edu_online_course_paediatric.cfm)), the EuTEACH-European Training in effective adolescent health and care ([www.unil.ch/euteach/en/home.html](http://www.unil.ch/euteach/en/home.html)) or the UK Adolescent Health Project ([www.e-lfh.org.uk](http://www.e-lfh.org.uk)). Reciprocal periods of training for members of the adult and paediatric rheumatology teams are advocated (Ideal).

**10. There must be secure funding for dedicated resources to provide uninterrupted clinical care and transition services for YP entering adult care.**

The following are regarded as essential for transitional care programmes;

- i) The funding and supporting resources for care should be dependent on clinical need and should not be interrupted on sole grounds on the age of the patient. Conversely, the presence or absence of resources should not define the timing of transfer.
- ii) Funding of (biological and other) therapies should continue if clinically indicated irrespective of patient age and transfer to adult care.
- iii) Funding of the paediatric and adult MDTs involved in the transitional care is needed.
- iv) The transition coordinator role and administration support for clinical networks must be funded.
- v) The training for the MDT along with continuous professional development support must be funded
- vi) The importance of adequate administrative support is likely to be a determinant of successful transfer.[45, 48, 80]

**11. There must be a freely accessible electronic-based platform to host the recommendations, standards, and resources for transitional care.**

An open resource e-platform (Essential), such as the EULAR / PReS website, to host resources to support the transition process, staff training and patient resources, would facilitate setting up of new and further development of existing transition services. All stakeholders must have access to these resources, including YP with jRMDs, their families and healthcare professionals in hospital, primary and community care involved. The resources must be endorsed (Essential) by professional bodies such as EULAR / PReS, consumer groups and charities in the respective countries.

### **12. Increased evidence-based knowledge and practice is needed to improve outcomes for YP with childhood onset RMD.**

The expert group recognised the need for a greater evidence base to inform best practice, the best metrics for measuring “success” and “outcome” of transitional care programmes and the impact of such programmes on YP with jRMDs.[7, 37, 38] The agenda for research needs to include,

- i) The transition programme evaluation as a complex intervention[74]
- ii) The effectiveness of the transition process[61] and how this can be measured
- iii) The timeliness of interventions and validation of readiness tools,[68-72, 81]
- iv) The outcome measures of transition [37-39, 41, 82] and
- v) Predictors for transition outcomes
- vi) Cohort studies and registries from paediatric rheumatology to extend into adult life
- vii) An agreed ‘core transition dataset’ for routine practice in paediatric and adult rheumatology centres to inform and foster future research initiatives, facilitate a standardised approach in transitional care and enable comparative assessment of care across Europe.

### **Standards and quality indicators**

The expert group concluded that there is a limited evidence base for outcomes of transition and for YP rheumatology services.[61] The expert group proposed, before the publication of the previous studies, key quality indicators to measure service delivery and to inform the research agenda. Supplementary table shows a list of standards and the agreed quality indicators.

In 2015, Suris *et al.* coordinated an international consensus on key elements and one indicator of a good transition.[79] In most instances, such consensus underscored items related to coordination and communication as basis for good partnership between paediatric and adult providers. Another initiative, developed during our project, obtained a clinical practice-benchmark tool for transition to adult care in the United Kingdom through a process of mapping.[83] There is no single outcome of ‘successful’ transition and potential indicators need to include clinical parameters (disease activity and status), patient (and family) experience (of care), psychosocial, educational and vocational status, quality of life measures, participation in adult life, engagement and attendance in adult health care, adherence to treatment, achievement of young adult developmental tasks. A recent taskforce identified, by Delphi methodology, outcomes of importance.[41] These included individual outcomes (quality of life, understanding the characteristics of conditions and complications, knowledge of medication, self-management, adherence to medication, and understanding health insurance), health

services outcomes (attending medical appointments, having a medical home, and avoidance of unnecessary hospitalization), and a social outcome (having a social network). Measures need to be valid, reproducible and relevant.

### DISCUSSION

This PReS / EULAR taskforce has developed the first international set of recommendations and standards for transitional care of YP with jRMDs; the aim being to facilitate high quality models of care for new and existing services, inform strategies for evaluation and define a research agenda. These were produced before the emergence of the 2016 NICE guidance on Transition in the UK ([www.nice.org.uk/guidance/ng43](http://www.nice.org.uk/guidance/ng43)) but reassuringly, are consistent NICE recommendations. Our methodology permitted critical appraisal of published models of care and incorporated opinion from a diverse expert specialists group including YP.[61] Our recommendations and standards set out the 'essential/minimal' and 'ideal/optimal' components of transitional care and we anticipate that such stratification will be helpful to benchmark services and facilitate implementation and evaluation.

The recommendations focus on transitional rheumatology care, however, they comprise components of high-quality transitional care derived from policy documents, guidelines relating to transitional care and the adolescent health literature. This underlines that, overall, most key elements of transitional care are generic. That is also reflected in the key elements for successful transition, which were published by Suris after the recommendations given here were agreed on.[79] Six elements were regarded as being essential by more than 70% of an international panel, of which two relate to establishing a good partnership between paediatric and adult professionals and the shared responsibility of transitional care. All six essential elements are included in the recommendations given here, which highlight the need for teams to work effectively together and engagement of different care providers within clinical networks. Addressing the challenges of 'joined up' working across paediatric and adult rheumatology and within clinical networks has also been highlighted by others.[84] Our recommendations, in agreement with other recent taskforces,[79, 83] emphasise the importance of identifying key individuals, the integral role of YP and families, written communication, agreed policy, training and clarity of roles within teams. Therewith, they focus on process areas that are most in need of improvement according to care providers and consumers, such as co-ordination, guidelines, protocols, and communication.[65] It is apparent that a transitional care pathway for YP with jRMDs can be implemented with a motivated health care team, the reorganisation of their existing work practice and available resources.[29, 31] The transitional care MDT also needs specific training in adolescent medicine and adequate capacity to enable the transition care coordinator role to function.[46, 48]. Transition is resource consuming. The expert panel stresses the fact that without sufficient funding or reimbursement of the specific interventions, transitional care services cannot

become a normal part of health care for young people. Funding is needed for specific service provision and to ensure continuity of clinical care and access to medicines after transfer to adult care based on clinical need rather than age of the patient of the provider. There are promising examples in the U.K. or Germany, where the provision of transitional care services as part of clinical practice has been funded by the government or statutory health insurance companies within defined programmes.[32] The funding for continuity of clinical care and access to medicines after transfer to adult care has to be addressed and based on clinical need rather than age of the patient of the provider. Given the importance of transition for the many YP who transfer to adult rheumatology, we strongly suggest that transitional care is included in all PReS and EULAR activities to raise awareness, promote access to training and improve skills and knowledge amongst all adult rheumatology teams.

Quality indicators and outcomes of transitional care are proposed. These transitional care outcomes are similar to most of 10 prioritized outcomes identified by a task force from the Health Care Transition Research Consortium [41] and may allow researchers to conduct focused evaluations of current processes and more detailed evaluations of interventions.

We acknowledge differences between countries in how transition may be organized within different health care systems.[65, 85-87] Our recommendations are intended to be useful, widely applicable and promote transitional care. Although transitional care has received much attention in the child health community, little government attention has been paid to this complex health system issue. An analysis of policy profiles of paediatric-to-adult care transitions in six European countries revealed that four had currently no transition policies or strategies.[87] The overarching principles seek to promote transferability to different contexts, be compliant with national regulatory guidance and facilitate local teams to work together with responsibility and accountability for services to be suitable for local needs. Our approach is similar to that proposed by others; the Spanish consensus for transition management in patients with jRMDs[88] reported a framework with similar recommendations albeit with more practical details suited to the Spanish health care system.

Transition is a time-variable process that prepares YP with jRMDs to take responsibilities for their lives and also their health issues. This process is critical in order to facilitate the actual transfer to adult care. Transition is therefore a complex process with many variables involved and the panel required considerable dialogue and indeed compromise to agree the aims, framework and process map to address such complexity. However, as the project evolved and moved forward, harmonisation became apparent and ultimately one round of Delphi was adequate to achieve high agreement.

It is clear that there are many unanswered questions in transitional care. Our recommendations highlight the need for improved evidence base to inform models of care, identify relevant outcome



measures and the cost effectiveness of transitional care programmes as a complex intervention. Much work is yet to be done, but it is important to identify and ultimately deliver 'best' care for YP with jRMDs and their families, to facilitate optimal physical, psychosocial and quality of life outcomes within adulthood.

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**Table 1.** Individuals to whom these recommendations may prove useful.

Adult and paediatric rheumatologists
<p>Other health care professionals:</p> <ul style="list-style-type: none"> <li>- nurses,</li> <li>- physiotherapists,</li> <li>- occupational therapists,</li> <li>- social workers,</li> <li>- psychologists,</li> <li>- youth workers,</li> <li>- primary care and other specialists (e.g., ophthalmology, dermatology, nephrology, orthopaedics) involved in share care and clinical networks</li> </ul>
General practitioners and health care professionals working in primary care
Young people with RMD and other multisystem disease, their families and peers
Professional groups or societies working with young people with RMDs
Academics involved in Adolescent and Young Adult health research
<p>In addition, these standards and recommendations are intended to be useful to the remit of:</p> <ul style="list-style-type: none"> <li>- Educational and vocational services</li> <li>- Employers and careers advisory services</li> <li>- Charities and support organisations</li> <li>- Funders of clinical services</li> <li>- Health policy makers</li> <li>- Research funding bodies</li> <li>- Organisers of disease and/or drug registers, and cohort studies</li> </ul>

**Table 2.** Recommendations, standards, and proposed quality indicators on transitional care for young persons with RMD

Recommendations	LOE	GR	MA
1. Young people (YP) with RMD should have access to high quality, coordinated transitional care, delivered through partnership with health care professionals, YP and their families, to address needs on an individual basis.	5	D	9.6
2. The transition process should start as early as possible; in early adolescence or directly after the diagnosis in adolescent-onset disease	2b	B	8.3
3. There must be 'direct' communication between the key participants (and as a minimum, to include the YP, parent/carer, and a member each of the paediatric and adult rheumatologist teams) during the process of transition. Before and after the actual transfer there should be 'direct' contacts between paediatric and adult rheumatologist teams.	5	D	9.3
4. Individual transition processes and progress should be carefully documented in the medical records and planned with YP and their families.	5	D	9.2
5. Every rheumatology service and clinical network—paediatric and adult—must have a written, agreed, and regularly updated transition policy.	5	D	8.9
6. There should be clear written description of the multidisciplinary team (MDT) involved in transitional care, locally and in the clinical network. The MDT should include a designated transition coordinator.	5	D	8.7
7. Transition services must be YP focused, be developmentally appropriate and address the complexity of YP development.	5	D	9.4
8. There must be a transfer document.	5	D	9.4
9. Health care teams involved in transition and adolescent-young adult care must have appropriate training in generic adolescent care and childhood onset RMD.	5	D	9.5
10. There must be secure funding for dedicated resources to provide uninterrupted clinical care and transition services for YP entering adult care.	5	D	9.4
11. There must be a freely accessible electronic-based platform to host the recommendations, standards, and resources for transitional care.	5	D	9.4
12. Increased evidence-based knowledge and practice is needed to improve outcomes for YP with childhood onset RMD.	5	D	8.5

Abbreviations: LOE, level of evidence; GR, grade of recommendation; MA, mean agreement (0-10)



**Table 3.** Aspects considered as part of holistic care.

<p>Medical aspects</p> <ul style="list-style-type: none"><li>• identification of medical needs, addressing any issues</li><li>• ensuring continuity of provision of high quality care</li><li>• providing generic and disease-specific information</li><li>• health promotion, anticipatory guidance</li><li>• health behaviour (e.g. health literacy, experimentation and risk behaviour), negotiating most appropriate ways to ensure adherence to treatment</li><li>• knowledge and skills in areas listed above</li></ul>
<p>Psychosocial aspects</p> <ul style="list-style-type: none"><li>• identifying individual needs, risk and protective factors (e.g. HEADSS),[89, 90]</li><li>• providing support or referring young people to specific agencies</li><li>• ensuring a social life that is equivalent to those of peers</li><li>• ensuring support to cope with disease/treatment</li><li>• providing advice and/or additional sources of support</li><li>• promoting skills in assertiveness, resilience, self-care, self-determination, and self-advocacy</li></ul>
<p>Educational and vocational aspects:</p> <ul style="list-style-type: none"><li>• addressing future career prospects</li><li>• developing skills in disclosure</li><li>• support in preparing for work readiness,</li><li>• informing about where to get information (recommend: career advisors, appropriate agencies, charity websites)</li><li>• addressing work experience and encouraging young people to gain relevant experience</li><li>• offer appropriate information, support and advice (support groups, volunteer services)</li><li>• liaisons with educational institutions</li><li>• informing about rights and obligations, benefits and opportunities to adapt working (place, time)</li></ul>

1 *(Supplementary material)*

## 2 Selected resources that may aid designing and maintaining transitional services.

Web site	Description	Useful to
<b>TRAINING RESOURCES</b>		
<a href="http://www.unil.ch/euteach/home.html">http://www.unil.ch/euteach/home.html</a>	Provides objectives, strategies and resources for trainers and teachers.	Healthcare professionals
<a href="http://www.e-lfh.org.uk/programmes/adolescent-health/">http://www.e-lfh.org.uk/programmes/adolescent-health/</a>	The Adolescent Health Programme (AHP) is an e-learning programme for all healthcare professionals working with young people.	Healthcare professionals
<a href="http://www.talklab.nhs.uk">http://www.talklab.nhs.uk</a>	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
<a href="http://www.usc.edu/adolhealth/">http://www.usc.edu/adolhealth/</a>	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
<b>GUIDANCE</b>		
<a href="http://www.cps.ca/en/documents/authors-auteurs/adolescent-health-committee#practice-points">http://www.cps.ca/en/documents/authors-auteurs/adolescent-health-committee#practice-points</a>	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.
<a href="http://www.adolescenthealth.org/Clinical-Care">http://www.adolescenthealth.org/Clinical-Care</a>	This site provides resources to adolescent and young adult health	Healthcare

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Web site	Description	Useful to
<a href="#">Resources/Clinical-Care-Resource-Guides.aspx</a>	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
<a href="https://www.nice.org.uk/guidance/ng43">https://www.nice.org.uk/guidance/ng43</a>	This guideline of the National Institute for health and Care Excellence includes recommendations for transition.	Healthcare professionals, young people and families.
<b>PROFESSIONAL ORGANISATIONS</b>		
<a href="http://www.yphsig.org.uk/">http://www.yphsig.org.uk/</a>	Home page of the Young People's Health Special Interest Group of the Royal College of Paediatrics and Child Health, UK	Healthcare professionals
<a href="http://www.adolescenthealth.org">http://www.adolescenthealth.org</a>	Home page of the Society for Adolescent Health and Medicine	Healthcare professionals
<a href="http://www.iaah.org">http://www.iaah.org</a>	Home page of the International Association for Adolescent Health	Healthcare professionals
<b>TRANSITIONAL CARE RESOURCES</b>		
<a href="http://www.gottransition.org/">http://www.gottransition.org/</a>	Include a complete compilation. Serve as a clearinghouse for current transition information, tools, and resources. Also in Spanish.	Healthcare professionals, young people and families.
<a href="http://depts.washington.edu/healthtr">http://depts.washington.edu/healthtr</a>	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.
<a href="http://chfs.ky.gov/ccshcn/ccshcntransition.htm">http://chfs.ky.gov/ccshcn/ccshcntransition.htm</a>	Interesting website with Transition Resources, ages adapted	Young people and

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Web site	Description	Useful to
		families
<a href="http://www.chla.org/my-voice-adolescent-transition-program">http://www.chla.org/my-voice-adolescent-transition-program</a>	Include information about Adolescent Transition Program	Young People and families
<a href="http://www.floridahats.org/">http://www.floridahats.org/</a>	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.
<a href="http://www.sickkids.ca/good2go/">http://www.sickkids.ca/good2go/</a>	This site provides resources to youth, families, and health care professionals.	Healthcare professionals, young people and families.
<a href="http://www.ontracbc.ca/">http://www.ontracbc.ca/</a>	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
<a href="http://www.transitioninfonyetwork.org.uk">http://www.transitioninfonyetwork.org.uk</a>	Provides information about the transition process that is useful to disabled young people, parents/carers and professionals.	Healthcare professionals, patients and families.
<a href="http://www.chimat.org.uk/transitions">http://www.chimat.org.uk/transitions</a>	Resources and evidence relating to young people's transition process into the adult world. It is regularly updated	Healthcare professionals, patients and families.
<a href="http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx">http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx</a>	Description of the Ready Steady Go transition programme. Include resources for health professionals and useful links	Young people, families and health care professionals

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Web site	Description	Useful to
<a href="http://www.rch.org.au/transition/">http://www.rch.org.au/transition/</a>	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.
<b>RHEUMATOLOGY-SPECIFIC</b>		
<a href="http://www.bspar.org.uk/adolescent-rheumatology">http://www.bspar.org.uk/adolescent-rheumatology</a>	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 <a href="http://www.pmmonline.org">http://www.pmmonline.org</a>	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
<a href="http://www.healthtalk.org/young-peoples-experiences/arthritis/transition-moving-adolescent-or-adult-services">http://www.healthtalk.org/young-peoples-experiences/arthritis/transition-moving-adolescent-or-adult-services</a>	This website provides free, reliable information about health issues, by sharing people's real-life experiences.	Young people
<a href="http://www.jatransition.org/">http://www.jatransition.org/</a>	Website designed to prepare youth with rheumatic diseases and their families for the transition to healthy adulthood.	Young people and families
<a href="http://www.arthritisresearchuk.org/youngpeople">http://www.arthritisresearchuk.org/youngpeople</a>	Includes practice information for young patients, parents and also for patient school teachers.	Young people and families
<a href="http://www.jia.org.uk/transition">http://www.jia.org.uk/transition</a>	Include useful resources about moving from paediatric to adult care. Includes a specific guide for parents	Young people and families
<a href="http://www.kidsgetarthritisoo.org/living-with-ja/daily-life/transition/">http://www.kidsgetarthritisoo.org/living-with-ja/daily-life/transition/</a>	Specifics resources for parents.	Families

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

1

2

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## 1 Standards at national level

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

## 7 Standards at unit level (minimum + ideal)

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

## 18 Standards at patient level (minimum + ideal)

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

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

4 **Quality indicators**

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

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



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

<p>1) Communication between health professionals and patient:</p> <ul style="list-style-type: none"><li>a) Developmentally-appropriate language, YP-oriented<ul style="list-style-type: none"><li>i) honest, realistic and jargon free</li><li>ii) supportive dialogue</li><li>iii) assisting young people to develop the communication skills that are necessary to manage and navigate services effectively</li><li>iv) establishing a positive therapeutic relationship that enables young people to express opinions and make informed decisions about care</li></ul></li><li>b) Offering opportunities (enough time, independent of caregivers/parents, appropriate environment, talk to peers) for communication</li><li>c) Developmentally-appropriate format (written, verbal, phone calls, emails, texting, referring to other forms of communication),</li><li>d) Explain and assure confidentiality (e.g. before discussing sensitive topics)</li></ul>
<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"><li>i) appropriate verbal and non-verbal communication</li><li>ii) referring to other forms of communication</li><li>iii) acknowledging parents knowledge base and pivotal role in caring</li><li>iv) offering available supporting services</li><li>v) respect rights to confidentiality of the young person</li></ul>
<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"><li>i) one member of the paediatric team: announcing transfer of patient</li><li>ii) one member of the adult team: feedback confirming that the patient has been seen for at least the first two visits in adult care.</li></ul>

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**EULAR / PReS standards and recommendations for the transitional care of young people  
with juvenile onset rheumatic diseases**

Authors

Helen E Foster\*

Kirsten Minden\*

Daniel Clemente

Leticia Leon

Janet E McDonagh

Sylvia Kamphuis

Karin Berggren

Philomine van Pelt

Carine Wouters

Jennifer Waite-Jones

Rachel Tattersall

Ruth Wyllie

Simon R Stones

Alberto Martini

Tamas Constantin

Susanne Schalm

Berna Fidanci

Burak Erer

Erkan Dermikaya

Seza Ozen

Loreto Carmona

\* Drs Foster and Minden contributed equally.

## ABSTRACT

**Aims.** To develop standards and recommendations for transitional care for young people (YP) with juvenile onset rheumatic and musculoskeletal diseases (jRMD).

**Methods.** The consensus process involved the following: 1) Establishing an international expert panel to include patients and representatives from multidisciplinary teams in adult and paediatric rheumatology 2) A systematic review of published models of transitional care in jRMDs, potential standards and recommendations, strategies for implementation and tools to evaluate services and outcomes; 3) Setting the framework, developing the process map and generating a first draft of standards and recommendations; 4) Further iteration of recommendations; 5) Establishing consensus recommendations with Delphi methodology; and 6) Establishing standards and quality indicators.

**Results.** The final consensus derived 12 specific recommendations for YP with jRMD focused on transitional care. These included: high quality, multidisciplinary care starting in early adolescence; the integral role of a transition coordinator; transition policies and protocols; efficient communications; transfer documentation; an open electronic-based platform to access resources; appropriate training for paediatric and adult health care teams; secure funding to continue treatments and services into adult rheumatology; and the need for increased evidence to inform best practice.

**Conclusions.** These consensus-based recommendations inform strategies to reach optimal outcomes in transitional care for YP with jRMD based on available evidence and expert opinion. They need to be implemented in the context of individual countries, health care systems and regulatory frameworks.

## INTRODUCTION

**Transitional care**, as defined by the Society for Adolescent Medicine, is "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems".[1] Transition does not only focus on the administrative event of transfer of care between paediatric and adult providers; transition encompasses the process by which young people (YP) acquire skills and access resources to ensure that their physical, psychosocial, educational and vocational needs are met during transition to adulthood.[2] Adolescence and young adulthood reflect an important and unique developmental period for all YP who need education, support, guidance and planning to prepare them to be appropriately responsible and accountable for their own health and well-being as adults.[3] The same principle applies to YP with chronic illnesses (including juvenile-onset rheumatic and musculoskeletal diseases [jRMDs]) who need to acquire additional skills to independently manage their chronic illness. The case of need for transition is well described and transitional care aims to provide support and guidance so that YP can acquire the necessary skills and knowledge required to be independent, empowered and responsible adults.[4-7]

The course of jRMDs often continues into adulthood; according to population-based inception cohort studies approximately half of YP with jRMDs enter adulthood with active disease, or develop flares of disease as adults. Many YP require ongoing and often long term treatment with complex immunosuppressive regimens.[8-10] Disease related sequelae are still observed, although with modern approaches to management, many YP are transferring to adult care in clinical remission albeit on medication.[11-13] All YP with jRMDs are, in principle, at significant risk of disability, early morbidity and limitations in participation later in life.[14, 15] These YP need continuous and developmentally appropriate care during and beyond adolescence to ensure optimal functioning in adulthood.

However, the literature informs us that currently up to half of the YP do not make a successful transfer to adult rheumatology and are therefore at particular risk of unfavourable outcomes.[16-18]

The importance of transitional care in YP with jRMD has been increasingly acknowledged.[19, 20]

There is evidence regarding 'best practice' for transitional care, with emphasis on a holistic 'life course' approach to care.[21-23] Several healthcare institutions, specialties, and disease specific subgroups have developed and implemented transition programmes.[24-34] However, there is lack of clarity regarding the impact of transition programme on outcomes, and indeed, variance in what the outcomes should be.[35-40] A first consensus-based proposal regarding outcome indicators for successful health care transition was recently made by an international group of interdisciplinary health care professionals, patients and their families.[41] With rheumatology, there are significant gaps in current delivery of transition services and these include the unmet training needs for health

care professionals in adolescent health and transitional care (resulting in lack of understanding and appreciation of the needs of YP), lack of transition readiness of YP (and/or of their parents/carers), and lack of robust quality indicators or cost-effective strategies.[2, 36, 42-48]

Despite the limitations of the existing programmes, the gaps in knowledge and the paucity of resources, there is nonetheless commitment within the rheumatology communities (both adult and paediatric), to improve existing transitional care services. There is a strong desire for rheumatology-specific guidelines for transition [48] and for these to be implemented across paediatric, adolescent and adult rheumatology health care settings.

### **Objectives, scope, users and overarching principles**

The objective of the present initiative was to develop recommendations and standards for transitional care for YP with jRMDs, spanning ages from early adolescence (defined as 10 to 13 years), mid adolescence (14-16 years), late adolescence (17 to 19 years) to young adulthood (20 to 24 years).[49, 50] These recommendations and standards are to be used to guide service development, benchmark the quality of transition services and be used by patient organisations to enhance patient expectations of care. We acknowledge that their implementation into clinical practice will be challenging and likely to be facilitated by stratification into ‘essential’ and ‘ideal’ components—**essential** defined as the *minimum* standards below which care would be deemed unacceptable and **ideal** being the standard that is regarded as excellent “optimal” care.

The purpose of these recommendations and standards is to increase the profile of transition, optimise delivery of transitional care and improve patient experience within rheumatology across European countries. Specifically, the objectives are:

- to ensure youth friendly and developmentally appropriate care
- to improve physical, psychological, social, vocational and illness-related outcomes of YP with jRMDs
- to facilitate continuity of care within adult rheumatology
- to promote evidence based practice in transitional care
- to facilitate clinical networks of health care professionals (paediatric and adult) who are engaged, interested and trained in the care of YP

The scope of these recommendations and standards refers to all persons involved in the care of YP with jRMDs that continue into adulthood including, but not restricted to, those in Table 1.

Although these recommendations and standards are related to the specific needs of YP with jRMDs, our expert panel endorse the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine consensus statement on health care transitions for YP with special health care needs,[51, 52] position papers of the Society for Adolescent Medicine,[1, 53-55] the Canadian Paediatric Society,[56] the Royal Australasian College of Physicians,[57] and the WHO definition of adolescent-friendly health services.[58, 59] In addition, we emphasise key components integral to these recommendations and standards, namely the importance of a YP focus, multidisciplinary approach with equity of access, quality of care and flexibility; the latter acknowledging both the heterogeneity of YP development and potential impact of chronic illness.

### **METHODS**

The consensus process underwent the following stages: 1) Establishing an international expert panel to include patients and representatives from multidisciplinary teams in adult and paediatric rheumatology; 2) A systematic literature review; 3) Setting the framework, developing the process map and generating a first draft of standards and recommendations; 4) Further iteration of recommendations; 5) Developing consensus recommendations with Delphi methodology; and 6) Establishing standards and quality indicators, as suggested by the EULAR Standard Operating Procedures.[60]

The project convenors (HF, KM, LC) liaised to appoint clinical fellows (DC, LL) to work on the project. They then convened an expert multidisciplinary panel from adult and paediatric rheumatology across Europe (doctors and allied health professionals with interest in transitional care) and patient representatives (YP with jRMDs invited from existing patient groups). The aim was for the panel to reflect the diversity of Europe (namely geography, health care systems and cultures).

A systematic literature review of existing models of transitional care in jRMD was performed, with emphasis on potential recommendations, standards, strategies for implementation and tools to evaluate services and outcomes.[61]

The first 'face-to-face' meeting of the expert panel discussed results of the systematic review and agreed the following:

- i) purpose of the project, timelines, roles and planned outputs
- ii) the 'process map' of transitional care using MindManager™ software

- iii) a draft proposal of recommendations and standards relating to different elements of the process map; the proposed list was circulated after the meeting by email to the expert group and further feedback requested.

A second 'face-to-face' meeting further refined the recommendations and standards based on feedback from the group. Appropriate quality indicators were also suggested for each recommendation and standard.

The recommendations and standards were then listed as statements. A wider audience of a total of 195 adult and paediatric rheumatology clinicians (doctors and allied health professionals) were then invited to take part in an e-survey and give opinion of their level of agreement with each statement. The e-survey was disseminated through email lists held by professional groups (such as PReS, EULAR and rheumatology societies in different countries). All responses were anonymised. Participants were asked for their level of agreement with each statement (using a 10 point Likert scale, with 0 = No agreement through to 10= Total agreement) and a ranking exercise to identify "minimal" and "optimal" standards for each recommendation. The target number of respondents for the e-survey was 100 and the level of agreement set at 80% for acceptance (lower levels were to be then discussed by the expert panel, with further iterations of the statements proposed and then a second e-survey, if needed, to be disseminated). Once agreement was reached, the methodologist (LC), together with the clinical fellows (DC, LL), graded the level of evidence for each recommendation based on the Oxford Levels of Evidence, 2011 (available at <http://www.cebm.net/index.aspx?o=5653>) and assigned relevant quality indicators where appropriate.

### RESULTS – The recommendations and standards

The recommendations and standards, reported as "minimal/essential" and "ideal/optimal" levels of care and quality indicators are listed below; they are also presented in table format with the level of evidence and agreement reached (Supplementary material).(Table 2).

- 1. YP with jRMDs should have access to high quality, coordinated transitional care, delivered through partnership with health care professionals, YP and their families, to address their needs on an individual basis.**

High quality care means holistic care (which covers medical, psychosocial, educational and vocational aspects; see table 3) with a multidisciplinary approach and is based upon regular assessments of the disease status in the context of developmental stage, life events and personal aspirations of YP. This care needs to be 'future-focussed', albeit not limited to young adulthood, in order to ensure optimal well-being.[19, 23]

Ideal- Provision of a broad set of health care services led by providers who have specialist knowledge about JRDs and adolescent health; Essential: care providers who refer to other agencies and services who can appropriately assist with transition issues.

**2. The transition process should start as early as possible; in early adolescence or directly after the diagnosis in adolescent-onset disease.**

Specifically for childhood onset diseases, the transition process should start by early adolescence (11 years) (Ideal) or 14 years at the latest (Essential) in order to allow the development of the necessary self-care skills and optimise educational and vocational outcomes.[62, 63] For YP who are diagnosed over the age of 14 years the transition process should start at the time of diagnosis with the skills and support for transition built up over time. The transition process or joint care programs should enclose early adulthood, because young adults continue to have difficulties making effective linkages with adult care. Brain development continues and risk behaviours remain and may increase in the third decade, which have to be considered by proactive and preventive care.[64]

**3. There must be 'direct' communication between the key participants (and as a minimum, to include the YP, parent/carer, and a member of each of the paediatric and adult rheumatologist teams) during the process of transition. Before and after the actual transfer there should be 'direct' contacts between paediatric and adult rheumatologist teams.**

A network of adult rheumatologists interested, engaged with and trained in adolescent rheumatology, must be identified and known to the paediatric rheumatology team. The network should work within agreed pathways to facilitate transition and expedite early, active planning of transition. Ideally, there should be a combined meeting between the young person and his or her family, the paediatric and adult health care provider.[65-67] As a minimum, there should be at least two 'direct' contacts by telephone or email between the paediatric and adult rheumatology team (and documented in a written communication); one before and one after the transfer. Copies of written communications are to be made available to YP and families. Online supplementary table contains suggested guidelines regarding the content and format of communications at different stages of transitional care.

**4. Individual transition processes and progress should be carefully documented in the medical records and planned with YP and their families.**

Documentation should support the YP engagement and self-management skills, resilience and readiness for transfer.[68-72] This documentation should be tailored to local services, shared with the YP, and contribute to the medical summary. The inclusion of sensitive or confidential information (e.g. abortion, mental health problems) should be discussed with the YP. Ideally, there is a specific written individual transition plan,[26] which can be derived from a transition plan or passport example, such as



<http://www.uhs.nhs.uk/Media/Controlleddocuments/Patientinformation/Childhealth/Ready-Steady-Go-Transition-plan.pdf>. [21] As a minimum, the existence of a transitional care process has to be documented in the medical records. **Additional resources are listed in Supplementary material.**

**5. Every rheumatology service and clinical network—paediatric and adult—must have a written, agreed, and regularly updated transition policy.**

Policies and protocols should be agreed with all major stakeholders, including YP, families and all health care professionals and as equal partners; [27, 33, 61] it is important to stress the need to include all specialists (and not just in rheumatology) and primary care physician(s) who are involved in the clinical care of YP with jRMD [28] Hospital or institutional managers will have to agree to these policies to facilitate appropriate resources to support their implementation within the clinical departments. As a minimum, there must be a transition policy and the documents should be updated at least every five years. It is acknowledged that there is need for flexibility of the arrangements in transition policy and care pathways at a network level.

**6. There should be clear written description of the multidisciplinary team (MDT) involved in transitional care, locally and in the clinical network. The MDT should include a designated transition coordinator.**

The team for transitional care should reflect the multidisciplinary approach, i.e. doctors and other health professionals, such as nurses, physical therapists, psychologists, occupational therapists (OT), and youth or social workers. [28, 73, 74] It is recognised that certain roles within transition are likely to be addressed by different members of the MDT. [75] In addition, it is acknowledged that the composition of MDTs is variable and that some members may have more than one role. Ideally, there is personal continuity in the health professionals within the MDT providing care. [43] This provision of roles and services may be shared with other specialist services and not devoted solely to jRMDs. There should be a nominated and identified member of the MDT who is responsible as transition coordinator (Essential). This person can be a nurse or other health professional and should liaise between adult and paediatric teams to ensure the coordination of care, facilitation of communication and implementation of the transitional care plan including transfer. [61]

**7. Transition services must be YP focused, be developmentally appropriate and address the complexity of YP development.**

Components of YP focused care need to include: accessibility to specialised health care, staff attitudes, communication, medical competency, guideline-driven care, age appropriate environments, and youth involvement in health care. [76] Ideally, there should be a care facility that is truly adolescent-friendly staffed by professionals with expertise in adolescent care. The care should be organised to minimise

the frequency of appointments and interruption to the daily life of YP. The aim of the consultations with the MDT is to enable YP to take lead role instead of the parent / carer(s), whilst also supporting the parent/carer(s) in their changing roles.[43, 77, 78]

YP with jRMDs should have access to peer discussion and support through advisory group(s) and charity networks. Signposting to such groups and networks is the responsibility of the clinic where the YP attends. As a minimum, transitional care services should be led by staff with expertise and training in adolescent and young adult healthcare.

### **8. There must be a transfer document.**

The format and content of transfer documents should be agreed by paediatric and adult teams and with patient input where possible. The transfer document should include, as a minimum, a medical summary with the diagnosis, any comorbidities, vaccinations, any complications of disease or treatments, the professionals involved in care, current and previous treatments (with reasons for changing treatments and any adverse events). Ideally, it should also include: i) Psychosocial aspects and educational / vocational status at the time of transfer, and ii) A report on self-management skills, to include readiness for transfer and procedural pain management strategies (e.g. for joint injections with or without general anaesthesia).[79]

This transfer document may also include contributions from members of the MDT as appropriate and if relevant. Any confidential information or sensitive information to be included in the transfer document should be discussed with the YP; if needed, this should be included in a separate letter to the adult rheumatologist and be written ahead of the first consultation with adult rheumatology. Copies of the transfer document should be available to YP themselves in an easy read format if appropriate, and to all health care providers, including primary care, involved in the young person's care.[80]

### **9. Health care teams involved in transition and adolescent-young adult care must have appropriate training in generic adolescent health and childhood onset RMD.**

All members of the clinical MDT (from adult and paediatric rheumatology) engaged in transition are to have training on adolescent health and the process of transition.[46, 48] As a minimum, the key training components to be covered are: 1) jRMDs (presentation in childhood, knowledge and approaches to management), 2) Adolescence health and the impact on jRMDs, 3) Skills and knowledge to address emotional, mental health and social issues, 4) Promotion of healthy lifestyle and generic health issues, 5) Promotion of self-management and shared decision making, 6) Communication skills with young people and their parent/carer(s).

These skills and knowledge can be acquired through different ways of learning (e.g. to include clinical experience, e-learning, and practical workshops) and should be a component of continuous professional development. There are many courses and e-learning opportunities available, such as the EULAR/PReS On-line Course in Paediatric Rheumatology ([www.eular.org/edu\\_online\\_course\\_paediatric.cfm](http://www.eular.org/edu_online_course_paediatric.cfm)), the EuTEACH-European Training in effective adolescent health and care ([www.unil.ch/euteach/en/home.html](http://www.unil.ch/euteach/en/home.html)) or the UK Adolescent Health Project ([www.e-lfh.org.uk](http://www.e-lfh.org.uk)). Reciprocal periods of training for members of the adult and paediatric rheumatology teams are advocated (Ideal).

**10. There must be secure funding for dedicated resources to provide uninterrupted clinical care and transition services for YP entering adult care.**

The following are regarded as essential for transitional care programmes;

- i) The funding and supporting resources for care should be dependent on clinical need and should not be interrupted on sole grounds on the age of the patient. Conversely, the presence or absence of resources should not define the timing of transfer.
- ii) Funding of (biological and other) therapies should continue if clinically indicated irrespective of patient age and transfer to adult care.
- iii) Funding of the paediatric and adult MDTs involved in the transitional care is needed.
- iv) The transition coordinator role and administration support for clinical networks must be funded.
- v) The training for the MDT along with continuous professional development support must be funded
- vi) The importance of adequate administrative support is likely to be a determinant of successful transfer.[45, 48, 80]

**11. There must be a freely accessible electronic-based platform to host the recommendations, standards, and resources for transitional care.**

An open resource e-platform (Essential), such as the EULAR / PReS website, to host resources to support the transition process, staff training and patient resources, would facilitate setting up of new and further development of existing transition services. All stakeholders must have access to these resources, including YP with jRMDs, their families and healthcare professionals in hospital, primary and community care involved. The resources must be endorsed (Essential) by professional bodies such as EULAR / PReS, consumer groups and charities in the respective countries.

### **12. Increased evidence-based knowledge and practice is needed to improve outcomes for YP with childhood onset RMD.**

The expert group recognised the need for a greater evidence base to inform best practice, the best metrics for measuring “success” and “outcome” of transitional care programmes and the impact of such programmes on YP with jRMDs.[7, 37, 38] The agenda for research needs to include,

- i) The transition programme evaluation as a complex intervention[74]
- ii) The effectiveness of the transition process[61] and how this can be measured
- iii) The timeliness of interventions and validation of readiness tools,[68-72, 81]
- iv) The outcome measures of transition [37-39, 41, 82] and
- v) Predictors for transition outcomes
- vi) Cohort studies and registries from paediatric rheumatology to extend into adult life
- vii) An agreed ‘core transition dataset’ for routine practice in paediatric and adult rheumatology centres to inform and foster future research initiatives, facilitate a standardised approach in transitional care and enable comparative assessment of care across Europe.

### **Standards and quality indicators**

The expert group concluded that there is a limited evidence base for outcomes of transition and for YP rheumatology services.[61] The expert group proposed, before the publication of the previous studies, key quality indicators to measure service delivery and to inform the research agenda. Supplementary table shows a list of standards and the agreed quality indicators.

In 2015, Suris *et al.* coordinated an international consensus on key elements and one indicator of a good transition.[79] In most instances, such consensus underscored items related to coordination and communication as basis for good partnership between paediatric and adult providers. Another initiative, developed during our project, obtained a clinical practice-benchmark tool for transition to adult care in the United Kingdom through a process of mapping.[83] There is no single outcome of ‘successful’ transition and potential indicators need to include clinical parameters (disease activity and status), patient (and family) experience (of care), psychosocial, educational and vocational status, quality of life measures, participation in adult life, engagement and attendance in adult health care, adherence to treatment, achievement of young adult developmental tasks. A recent taskforce identified, by Delphi methodology, outcomes of importance.[41] These included individual outcomes (quality of life, understanding the characteristics of conditions and complications, knowledge of medication, self-management, adherence to medication, and understanding health insurance), health

services outcomes (attending medical appointments, having a medical home, and avoidance of unnecessary hospitalization), and a social outcome (having a social network). Measures need to be valid, reproducible and relevant.

### DISCUSSION

This PReS / EULAR taskforce has developed the first international set of recommendations and standards for transitional care of YP with jRMDs; the aim being to facilitate high quality models of care for new and existing services, inform strategies for evaluation and define a research agenda. These were produced before the emergence of the 2016 NICE guidance on Transition in the UK ([www.nice.org.uk/guidance/ng43](http://www.nice.org.uk/guidance/ng43)) but reassuringly, are consistent NICE recommendations. Our methodology permitted critical appraisal of published models of care and incorporated opinion from a diverse expert specialists group including YP.[61] Our recommendations and standards set out the 'essential/minimal' and 'ideal/optimal' components of transitional care and we anticipate that such stratification will be helpful to benchmark services and facilitate implementation and evaluation.

The recommendations focus on transitional rheumatology care, however, they comprise components of high-quality transitional care derived from policy documents, guidelines relating to transitional care and the adolescent health literature. This underlines that, overall, most key elements of transitional care are generic. That is also reflected in the key elements for successful transition, which were published by Suris after the recommendations given here were agreed on.[79] Six elements were regarded as being essential by more than 70% of an international panel, of which two relate to establishing a good partnership between paediatric and adult professionals and the shared responsibility of transitional care. All six essential elements are included in the recommendations given here, which highlight the need for teams to work effectively together and engagement of different care providers within clinical networks. Addressing the challenges of 'joined up' working across paediatric and adult rheumatology and within clinical networks has also been highlighted by others.[84] Our recommendations, in agreement with other recent taskforces,[79, 83] emphasise the importance of identifying key individuals, the integral role of YP and families, written communication, agreed policy, training and clarity of roles within teams. Therewith, they focus on process areas that are most in need of improvement according to care providers and consumers, such as co-ordination, guidelines, protocols, and communication.[65] It is apparent that a transitional care pathway for YP with jRMDs can be implemented with a motivated health care team, the reorganisation of their existing work practice and available resources.[29, 31] The transitional care MDT also needs specific training in adolescent medicine and adequate capacity to enable the transition care coordinator role to function.[46, 48]. Transition is resource consuming. The expert panel stresses the fact that without sufficient funding or reimbursement of the specific interventions, transitional care services cannot

become a normal part of health care for young people. Funding is needed for specific service provision and to ensure continuity of clinical care and access to medicines after transfer to adult care based on clinical need rather than age of the patient of the provider. There are promising examples in the U.K. or Germany, where the provision of transitional care services as part of clinical practice has been funded by the government or statutory health insurance companies within defined programmes.[32] The funding for continuity of clinical care and access to medicines after transfer to adult care has to be addressed and based on clinical need rather than age of the patient of the provider. Given the importance of transition for the many YP who transfer to adult rheumatology, we strongly suggest that transitional care is included in all PReS and EULAR activities to raise awareness, promote access to training and improve skills and knowledge amongst all adult rheumatology teams.

Quality indicators and outcomes of transitional care are proposed. These transitional care outcomes are similar to most of 10 prioritized outcomes identified by a task force from the Health Care Transition Research Consortium [41] and may allow researchers to conduct focused evaluations of current processes and more detailed evaluations of interventions.

We acknowledge differences between countries in how transition may be organized within different health care systems.[65, 85-87] Our recommendations are intended to be useful, widely applicable and promote transitional care. Although transitional care has received much attention in the child health community, little government attention has been paid to this complex health system issue. An analysis of policy profiles of paediatric-to-adult care transitions in six European countries revealed that four had currently no transition policies or strategies.[87] The overarching principles seek to promote transferability to different contexts, be compliant with national regulatory guidance and facilitate local teams to work together with responsibility and accountability for services to be suitable for local needs. Our approach is similar to that proposed by others; the Spanish consensus for transition management in patients with jRMDs[88] reported a framework with similar recommendations albeit with more practical details suited to the Spanish health care system.

Transition is a time-variable process that prepares YP with jRMDs to take responsibilities for their lives and also their health issues. This process is critical in order to facilitate the actual transfer to adult care. Transition is therefore a complex process with many variables involved and the panel required considerable dialogue and indeed compromise to agree the aims, framework and process map to address such complexity. However, as the project evolved and moved forward, harmonisation became apparent and ultimately one round of Delphi was adequate to achieve high agreement.

It is clear that there are many unanswered questions in transitional care. Our recommendations highlight the need for improved evidence base to inform models of care, identify relevant outcome

measures and the cost effectiveness of transitional care programmes as a complex intervention. Much work is yet to be done, but it is important to identify and ultimately deliver 'best' care for YP with jRMDs and their families, to facilitate optimal physical, psychosocial and quality of life outcomes within adulthood.

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**Table 1.** Individuals to whom these recommendations may prove useful.

Adult and paediatric rheumatologists
<p>Other health care professionals:</p> <ul style="list-style-type: none"> <li>- nurses,</li> <li>- physiotherapists,</li> <li>- occupational therapists,</li> <li>- social workers,</li> <li>- psychologists,</li> <li>- youth workers,</li> <li>- primary care and other specialists (e.g., ophthalmology, dermatology, nephrology, orthopaedics) involved in share care and clinical networks</li> </ul>
General practitioners and health care professionals working in primary care
Young people with RMD and other multisystem disease, their families and peers
Professional groups or societies working with young people with RMDs
Academics involved in Adolescent and Young Adult health research
<p>In addition, these standards and recommendations are intended to be useful to the remit of:</p> <ul style="list-style-type: none"> <li>- Educational and vocational services</li> <li>- Employers and careers advisory services</li> <li>- Charities and support organisations</li> <li>- Funders of clinical services</li> <li>- Health policy makers</li> <li>- Research funding bodies</li> <li>- Organisers of disease and/or drug registers, and cohort studies</li> </ul>

**Table 2.** Recommendations, standards, and proposed quality indicators on transitional care for young persons with RMD

Recommendations	LOE	GR	MA
1. Young people (YP) with RMD should have access to high quality, coordinated transitional care, delivered through partnership with health care professionals, YP and their families, to address needs on an individual basis.	5	D	9.6
2. The transition process should start as early as possible; in early adolescence or directly after the diagnosis in adolescent-onset disease	2b	B	8.3
3. There must be 'direct' communication between the key participants (and as a minimum, to include the YP, parent/carer, and a member each of the paediatric and adult rheumatologist teams) during the process of transition. Before and after the actual transfer there should be 'direct' contacts between paediatric and adult rheumatologist teams.	5	D	9.3
4. Individual transition processes and progress should be carefully documented in the medical records and planned with YP and their families.	5	D	9.2
5. Every rheumatology service and clinical network—paediatric and adult—must have a written, agreed, and regularly updated transition policy.	5	D	8.9
6. There should be clear written description of the multidisciplinary team (MDT) involved in transitional care, locally and in the clinical network. The MDT should include a designated transition coordinator.	5	D	8.7
7. Transition services must be YP focused, be developmentally appropriate and address the complexity of YP development.	5	D	9.4
8. There must be a transfer document.	5	D	9.4
9. Health care teams involved in transition and adolescent-young adult care must have appropriate training in generic adolescent care and childhood onset RMD.	5	D	9.5
10. There must be secure funding for dedicated resources to provide uninterrupted clinical care and transition services for YP entering adult care.	5	D	9.4
11. There must be a freely accessible electronic-based platform to host the recommendations, standards, and resources for transitional care.	5	D	9.4
12. Increased evidence-based knowledge and practice is needed to improve outcomes for YP with childhood onset RMD.	5	D	8.5

Abbreviations: LOE, level of evidence; GR, grade of recommendation; MA, mean agreement (0-10)

**Table 3.** Aspects considered as part of holistic care.

<p>Medical aspects</p> <ul style="list-style-type: none"><li>• identification of medical needs, addressing any issues</li><li>• ensuring continuity of provision of high quality care</li><li>• providing generic and disease-specific information</li><li>• health promotion, anticipatory guidance</li><li>• health behaviour (e.g. health literacy, experimentation and risk behaviour), negotiating most appropriate ways to ensure adherence to treatment</li><li>• knowledge and skills in areas listed above</li></ul>
<p>Psychosocial aspects</p> <ul style="list-style-type: none"><li>• identifying individual needs, risk and protective factors (e.g. HEADSS),[89, 90]</li><li>• providing support or referring young people to specific agencies</li><li>• ensuring a social life that is equivalent to those of peers</li><li>• ensuring support to cope with disease/treatment</li><li>• providing advice and/or additional sources of support</li><li>• promoting skills in assertiveness, resilience, self-care, self-determination, and self-advocacy</li></ul>
<p>Educational and vocational aspects:</p> <ul style="list-style-type: none"><li>• addressing future career prospects</li><li>• developing skills in disclosure</li><li>• support in preparing for work readiness,</li><li>• informing about where to get information (recommend: career advisors, appropriate agencies, charity websites)</li><li>• addressing work experience and encouraging young people to gain relevant experience</li><li>• offer appropriate information, support and advice (support groups, volunteer services)</li><li>• liaisons with educational institutions</li><li>• informing about rights and obligations, benefits and opportunities to adapt working (place, time)</li></ul>