

# The impact of juvenile onset rheumatic and musculoskeletal diseases on education, vocation and employment

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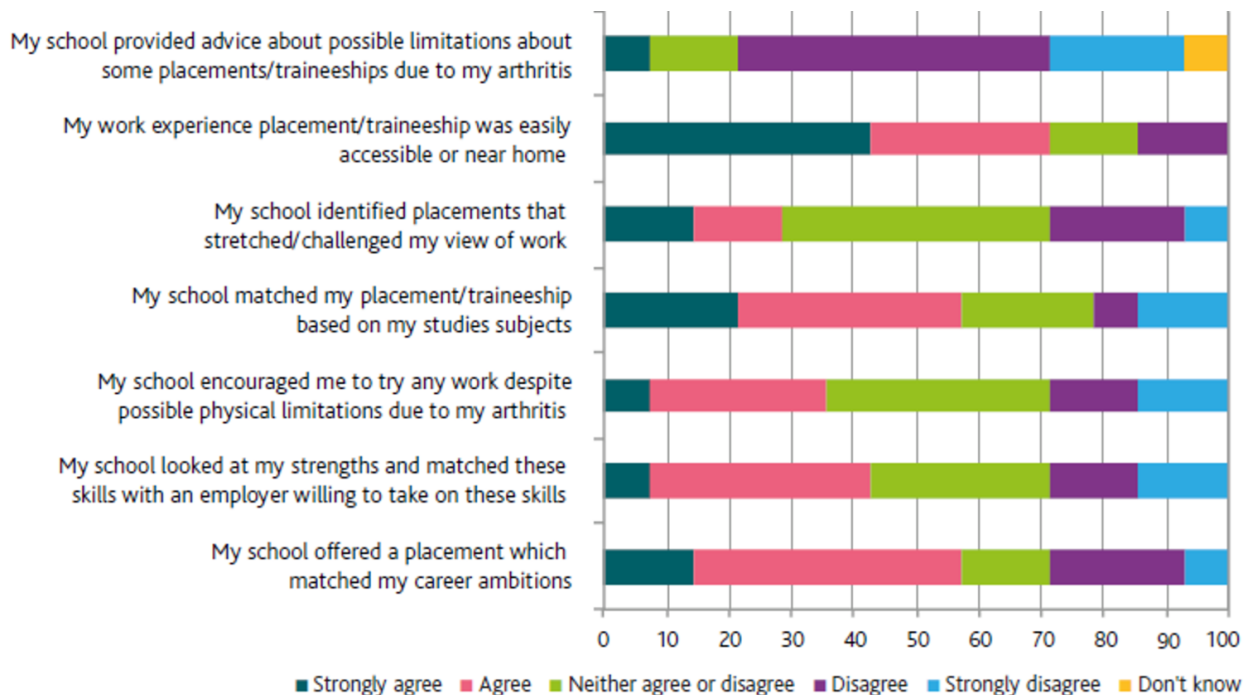


Figure 1. Work experience support and advice (Source NRAS WorkMatters 2017)

## Professor Suzanne Verstappen discusses the impact and challenges associated with juvenile-onset rheumatic and musculoskeletal diseases when navigating education and employment

Juvenile onset rheumatic and musculoskeletal diseases (jRMDs), such as juvenile idiopathic arthritis (JIA), lupus and vasculitis, are chronic diseases with onset before the age of 16 years. These conditions can cause persistent joint pain, swelling of the joints and stiffness. Other symptoms include fatigue and functional disability. These symptoms may fluctuate, and sometimes, children and young adolescents with jRMDs have severe symptoms, whilst, on different days, they may feel better.

Some children may experience the symptoms only for a couple of months or years, whilst others have symptoms for many years and continue to have symptoms during adulthood. Some types of jRMDs can cause serious complications, such as joint damage, growth problems and inflammation of the eyes. Although disease management has improved in the last decade with more effective drugs and multidisciplinary care, the symptoms, adverse events due to medication use and clinical visits may impact school attendance, career choices and future employment.

## Impact of juvenile onset rheumatic diseases on education, vocation and employment

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Young adolescents with jRMD have highlighted the importance of research in the field of education, vocation and employment. The transition between education and finding a first job can be challenging for many young adults. Receiving the right career advice, finding a job, becoming financially independent, and having (short-term) contracts are all factors young people entering the workplace face. Still, they may be even more challenging for those with juvenile onset chronic conditions such as jRMDs.

These conditions are further influenced by wider health determinants such as gender, ethnicity and deprivation, factors which are also associated with worse educational and work outcomes, resulting in possible unequal opportunities to participate in education and successful employment. For young adolescents with jRMD, it is important that they receive the right help during their journey from being in education, making career choices and entering the labour market. This includes teachers at school, family, friends, career advisors, health professionals, patient organisations, government and employers.

### Education and vocation

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In 2017, the National Rheumatoid Arthritis Society (NRAS), together with the [University of Manchester](#) (Professor Suzanne Verstappen), conducted the WorkMatters survey for people with rheumatoid arthritis and adolescents and young adults with JIA. <sup>(1,2)</sup> The survey was completed by 19 young adolescents (aged 16-39 years) with JIA. Although the study sample was relatively small, two-thirds (67.7%) of the participants said their JIA had affected their school because of difficulties focusing, difficulties with writing, and time missed due to illness. The survey also included questions about work experience (Figure 1); 70% of respondents felt their school needed to provide advice about limitations they might face on a work-related placement or traineeship due to their JIA. Fourteen patients completed the question about career plans; 57.1% said they changed/ compromised their career plans because of JIA. The most common reasons for changing their career were wanting to stay healthy, JIA-related symptoms such as sore joints and fatigue and choosing a career path that was too physically demanding.

Young adolescents with jRMDs whose symptoms persist into adulthood also face additional challenges transitioning from paediatric rheumatology care to adult rheumatology care. We recently published a systematic review to assess education and employment outcomes in the provision of healthcare for young people with long-term physical conditions. <sup>(3)</sup> We found that appropriate educational and employment interventions in translational care were missing and that with minimal adaptations, transitional care interventions would be well suited to deliver this. It is important that questions about education, vocation and employment are addressed in the clinic and, where necessary, young adolescents with jRMD are signposted to other health professionals (e.g. occupational therapists and physiotherapists with expertise in the area) or other relevant resources.

## Working with juvenile-onset rheumatic and musculoskeletal diseases

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Young people applying for their first job might be quite anxious about the processes involved in applying for a job and becoming an employee. For those with a chronic disease such as jRMD, there may be additional barriers and questions such as ‘Should you disclose your disability, and when or not?’ ‘Will the job fit the expectations?’ ‘How demanding will the job be, and how may this impact the disease?’. The choice of a first job may impact on the future career and whether one will be able to remain in employment. Most research to date has focused on the impact of employment in adult-onset rheumatological conditions such as rheumatoid arthritis, and not on jRMD. People with rheumatoid arthritis are more likely to take sick leave, report presenteeism (i.e. reduced productivity due to ill health whilst at work) and may have to stop working due to their condition. <sup>(4,5)</sup> This will lead to high costs for society and the employer but will also have substantial financial consequences for the patient and their families, which may further impact their quality of life. It is important to gain an understanding of the socioeconomic consequences of rheumatic diseases later in life and also across the life course and to ensure the right support.

To address the importance of working and supporting people with RMDs across the life course in work, an international task force developed recommendations for people with adult and juvenile-onset RMDs (2021 European Alliance of Associations for Rheumatology (EULAR) points to consider supporting people with rheumatic and musculoskeletal diseases to participate in healthy and sustainable paid work). <sup>(6)</sup> Based on scientific evidence and expert opinions, a number of recommendations have been included in this report. Throughout their working life, people with RMDs should be supported and encouraged to enter, sustain and/or return to work. This recommendation is especially important for adolescents and young adults with jRMD. To achieve this goal, health professional organisations, policymakers, patient organisations and employers should collaborate to minimise the employment gap and optimise employment opportunities among people with adult and juvenile-onset RMDs. Healthcare providers (e.g. rheumatologists, occupational therapists, physiotherapists) are key in providing advice on how to overcome some of the fears young adults with jRMD may have when entering the labour market or when in employment, advice on how to manage work-life balance, possible adaptations needed at work, and disease management. There is a further need for policymakers to gain a better understanding of the needs of young adults with chronic disabilities entering the labour market in a changing working environment. Schemes such as Access to Work should also be widely advertised to this population. For employers, rheumatic diseases are often seen as diseases only affecting older people. It is important to raise more awareness amongst employers and line managers that RMDs can affect people of all ages. A better understanding among employers and line managers will also facilitate communication about possible support needed to work. This support can include flexible working, short breaks, travel arrangements for work, physical adaptations, signposting to services within the organisation or outside, and arrangements for clinical visits, etc. <sup>(7)</sup>

## Need for further data on the impact of juvenile-onset rheumatic and musculoskeletal diseases on education, vocation and employment

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There is a clear need from patients, families of adolescents and young adults with jRMD, patient organisations, career advisors, those working in education, healthcare professionals, policymakers and employers to gain a better understanding of the impact of jRMD on education, vocation and employment. The University of Manchester (PI Professor Suzanne Verstappen), in collaboration with Great North Children's Hospital, Liverpool University Hospital NHS Foundation Trust and the University of Dundee, is currently conducting the JOURNEY study (Juvenile Onset rheumatic diseases: edUcation, vocational ReadiNess, & EmploYment) (funding Nuffield Foundation Oliver Bird fund & Versus Arthritis). The overall aim of the JOURNEY study is to gain an in-depth understanding of the impact of jRMDs in adolescents and young adults (AYA) on education, vocation, and employment. In addition, we will also investigate the impact the disease has on parents and carers of those caring for or living with someone with jRMD.

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