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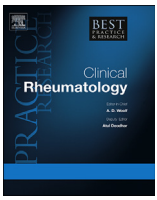

Improving musculoskeletal health for children and young people – A 'call to action'

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A B S T R A C T

This chapter describes the musculoskeletal (MSK) context in children and young people as an important contributor to the global non-communicable disease burden. Through selected MSK conditions, we describe the impact on patients, families and communities and highlight the challenges that need to be addressed. We focus on opportunities for better working together and describe exemplar initiatives to raise awareness, workforce capacity building, models of care and research agendas to have a greater global context.

Abbreviations: AHPs, allied health professionals; CYP, children and young people; EML, essential medicines list; HCPs, healthcare professionals; HRIC, high resource income countries; JIA, juvenile idiopathic arthritis; JSLE, juvenile systemic lupus erythematosus; LRIC, low resource income countries; MSK, musculoskeletal; MRIC, middle resource income countries; NCD, non-communicable diseases; pGALS, paediatric gait arms legs and spine; PMM, paediatric musculoskeletal matters; PReS, Paediatric Rheumatology European Society; SCFE, slipped capital femoral epiphysis; TEV, talipes equinovarus; UN, United Nations; WHO, World Health Organisation; CPD, continuous professional development.

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Introduction

The Paediatric Task Force for Global Musculoskeletal (MSK) Health (https://gmusc.com) is a virtual community with a shared vision of 'working better together' to improve the lives of children and families (Table 1). Our focus encompasses the breadth of rheumatology and orthopaedics and optimising MSK health through diet and lifestyle to reduce MSK burden across the life course. Our overarching mission is to raise awareness that *more needs to be done and can be achieved* through tangible solutions, sharing good practice and learning from each other. The Task Force has gathered considerable momentum with our chair (HF), co-chairs (CS, CT, MD), regional 'spokespersons' from around the globe and over 300 members, including healthcare professionals (HCPs) – doctors, nurses, allied health – and representatives from patient groups and professional societies.

This chapter describes the MSK context in children and young people (CYP) as an important contributor to the global non-communicable disease (NCD) burden. Through selected MSK conditions, we describe impact and challenges to be addressed. We describe exemplar initiatives to raise awareness, workforce capacity building, models of care and research agendas to have a greater global context.

Practice points

- What we know. The outcome for many childhood onset musculoskeletal (MSK) diseases has improved markedly with better treatment options, but inequity in access to right care' is a widespread global problem, not just low-income settings and poor access to medicines and specialist care, but compounded by remote geography, extremes of climate, cultural beliefs, poor transport and communication networks.
- What we think we know. Strategies to invest in young people to improve MSK health through lifestyle (diet, exercise) and reducing injuries will have benefit throughout the life course. Raising awareness, implementation of contextually relevant models of care, research agendas, workforce capacity building are keys to improving clinical outcomes for children with MSK conditions.
- What we do not know. The scale of the MSK burden in children around the world is unclear, but likely far greater than previously realised. How to address the unmet need remains a significant challenge with many unknowns. Solutions are likely to come from all stakeholders working together to identify priorities and inform strategies.

Research agenda

- There is need for robust data and epidemiological research to describe and assess the magnitude and impact of musculoskeletal (MSK) ill health in children around the world. Without data and research, patients in low resource settings will remain invisible, undiagnosed and inadequately managed.
- There is great potential for inventive and novel drug development/repurposing as many low resource income countries have well-funded research units working on infectious disease, with excellent immunology and basic science expertise. Utilising this local expertise to develop collaborative, cross platform, novel and creative research questions and hypotheses is vital and likely will have wide-reaching benefit.
- There is need for clinical trials to include low resource settings and consider protocols to include less costly interventions.

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- Policy based on consensus and evidence-based recommendations, standards of care and treatment guidelines for clinical care are important to leverage better care for patients and work is needed to ensure relevance to resource-poor settings.
- The World Health Organisation essential medicines list (EML) informs national formularies and especially in low resource income countries. Work is needed to revise the EML content for paediatric rheumatology.
- Models of care to address local' need requires stakeholders to think innovatively and modify existing models while addressing workforce capacity implications and setting-relevant metrics to evaluate implementation on clinical care and patient outcomes.
- The role of e-technologies in models of care, education and training has huge potential to expand with wide reach to include low resource settings.

Inequity, burden and challenges

Approximately, one in three people worldwide (about 2 billion people) live with a chronic MSK condition and often with pain, disability, mental ill health and increased risk of developing other chronic health conditions and all-cause mortality [8–11]. Indications from Global Burden of Disease Studies shows a steady increase in the relative burden of MSK conditions from 2.5% in 2004 to 5.9% 2016 [12–14]. The Global Burden of Disease profiles are undergoing an epidemiological shift from communicable, neonatal, maternal and nutritional health conditions to predominantly long-term NCDs especially as the global population is now living longer [8]. The steepest trajectory of rise is observed in low-income settings [15] and often aggravated by delayed diagnosis arising from poor education, sociocultural beliefs, poverty and limited access to healthcare [16].

The 'cost' of the MSK burden to individuals, families and communities is huge. Impaired MSK health is responsible for the greatest loss of productive life years in the workforce compared with other NCDs [17], and in low- and middle-income economies (LRIC and MRIC, respectively), has profound consequences for participation in society and prosperity of communities [18]. For CYP, the additional impact on education and psychosocial development cannot be underestimated with likely huge adverse consequences into adulthood.

The number of CYP affected with an MSK condition is less well understood. The term 'MSK' encompasses a heterogeneous range of congenital/developmental conditions (*such as clubfoot, developmental dysplasia of the hip and some forms of scoliosis*), a wide range of acquired diseases (*within rheumatology, orthopaedics, metabolic bone diseases and neuromuscular medicine*) and covering a multitude pathologies (*infection, inflammatory, malignancy, vascular, trauma, metabolic and nutritional*). The relative frequency of MSK pathologies varies across age groups (as exemplified by orthopaedic hip conditions with Legg–Calve–Perthes disease being more common in 5–10-year olds and slipped capital femoral epiphysis (SCFE) being more common in adolescence. The epidemic of obesity [19] and sedentary lifestyles further contributes to overall MSK burden in CYP with increasing prevalence of back pain [20] and chronic pain [21,22], which are all likely to impact adult life [9,11]. Globally, the

Table 1
Aims of the paediatric MSK global task force.

To Raise Awareness
• About the many children and young people around the world with MSK problems
• About the considerable long-term impact of untreated MSK conditions starting in early life: impact on young people, their families, carers and society
• That many conditions are treatable; long-term disability can be avoided thus reducing 'cost' to individuals and society
To Identify and Promote tangible exemplar solutions to better access to 'right' care
• Models of clinical care and availability of medicines
• Education and training for the workforce
• Patient and public involvement and engagement
To Promote healthy joints and bones
• Through lifestyle (e.g. diet, exercise, behaviours) to prevent obesity
• Reduce the risk of injury and prevent obesity
• Reduce the long-term risk of osteoarthritis and osteoporosis

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number of obese boys and girls has increased from 6 million and 5 million, respectively, in 1975 to 74 million and 50 million in 2016; a harbinger of a profound increase in long-term MSK health conditions [23,24]. Precise epidemiological data are not available on all MSK conditions; population studies suggest that one in three adolescent self-report MSK pain at least monthly [22] and a primary care study in the UK reported one in eight children [25] to have an MSK problem, which may be self-limiting (e.g. related to trauma or minor trauma) or serious with potential for increased mortality and high morbidity. The prevalence of MSK consultations to healthcare in children is relatively high and appears to increase with age (from 6% of 7-year olds to 16% of 22-year olds) [26] in one multi-birth cohort study from the UK and, therefore, imposes a significant burden on the healthcare system. A 'door-to-door' prospective survey in Rwanda found that MSK impairment was present in 2.6% of all children under 16 years of age, nearly half of whom required surgery [27]. Infectious causes of MSK disability, such as tuberculosis (TB) and septic arthritis disproportionately affect children in LRIC; although MSK TB comprises <10% of active TB cases, with over 10 million cases of active TB per year, the burden is significant, especially in areas where HIV co-infection is common [13]. There is estimated to be at least 2 million CYP who have one form of arthritis or another [28,29] and many live in the most populated and least well-resourced countries in Asia and Africa [29]. The WHO estimates 20–50 million people every year are injured in road traffic accidents and these are the leading cause of death for those aged 5–29 years [14,30]; more than 90% of road traffic deaths occur in resource poor countries with highest death rates in Africa. Even within high resource income countries (HRIC), people from lower socio-economic backgrounds are more likely to be involved in road traffic accidents and people are less likely to use active transport like walking, cycling and public transport in an unsafe environment [30].

In many LRIC and MRIC, despite sustained economic growth and development, there still remains profound inequity in the access to nutrition, water, sanitation, housing, physical safety and education [16]. CYP under the age of 16 constitute at least 26% of the world population and this is greater in many LRICs; for example, in 2019, in Africa, 41% of the population was aged under 16 years [31]. The challenges for CYP with MSK diseases and especially in LRIC are further compounded by poor access to clinical care and medicines, poor diagnostic capabilities and the deployment of human healthcare resources including paediatricians prioritised towards infectious and traumatic conditions [5,32,33]. The disparity in healthcare workers is massive when one considers the difference between Zambia (1.6/10,000) or Thailand (4.4/10,000) compared with the USA (25/10,000) or Spain (38/10,000) [34]. The situation is worse when one considers specialists in MSK health; sub-Saharan Africa has 16 trained paediatric rheumatologists, of whom 10 are in South Africa (giving a total 1 for every 37 million CYP), Asia has 1 for every 26 million children [28] and the USA 1 per 250,000 children [35]. Such inequity is reflected in evidence that CYP with juvenile idiopathic arthritis (JIA) have worse clinical outcomes in countries with lower gross domestic product (GDP) [36] with likely explanatory factors including delay in diagnosis, inadequate access to treatments and paucity of specialist care [5,37]. Inequity in 'access to right care' is a widespread global problem, not just LRIC, compounded by remote geography, extremes of climate, cultural beliefs, poor transport and communication networks [37].

In summary, MSK health is critical for function and active participation in all aspects of life and is therefore essential for maintaining economic, social and functional independence, as well as 'human capital' across the life course [8]. The disparities in healthcare distribution is not likely to be resolved in a matter of years or even decades; alternative approaches will be required to provide relief to current and future generations. Policies, strategies and health programmes for NCDs as well as essential care packages for WHO Universal Health Coverage (UHC) [38] are needed with a renewed and sustained focus on improving MSK across the life course particularly programmes targeting lower socioeconomic settings [8]. There is need for strategies focussed on prevention, promotion of healthy lifestyles, diagnostics, workforce capacity building and cost-effective interventions relevant to HRIC and LRIC [8,39,40].

Impact described through selected MSK conditions

Here, we describe selected MSK conditions to highlight impact, consequences of inadequate access to the right care and outline challenges to be addressed.

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Clubfoot

Talipes equinovarus (TEV), commonly referred to as clubfoot, is one of the most common birth defects involving the MSK system, with a global incidence of 1 in 500 births [41]; affecting over 2 million children around the world with 100,000 newly affected babies born each year [42]. Clinically, clubfoot is a rigid deformity and without treatment results in pain and disability long term [43]. Traditional shoe wear is not possible for those with an untreated clubfoot as the affected foot is twisted inwards so weight-bearing actually occurs on the top of the foot. While the incidence of clubfoot is fairly consistent around the world, the burden of clubfoot is disproportionately found in LRIC and MRIC in the most populated countries mostly in Africa and Asia [29], where 80% of the untreated or neglected clubfeet are located [29,42]. Individuals with clubfoot face incredible hurdles throughout their whole lives with stigma, discrimination, loneliness and being hidden away because the family feel ashamed; they are among the least likely to enjoy the benefits of education and healthcare and even worse, are subject to higher risks of neglect, poverty, physical and sexual abuse [44]. The aetiology of clubfoot is not clear – approximately, 80% are isolated birth defects and are considered idiopathic, while the remaining 20% are associated with known chromosomal abnormalities and genetic syndromes [45,46]; TEV is heritable, with familial recurrence rates of approximately 25% and concordance of 0.32 in monozygotic twins compared with only 0.029 in dizygotic twins [47–49].

Historically, treatment of clubfoot has consisted of an invasive and morbid surgery; many patients treated in this manner develop pain, arthritis, and difficulty ambulating as adults [50]. Fortunately, the Ponseti method of serial casting, a percutaneous tenotomy of the Achilles tendon, and foot abduction bracing have become the gold standard of treatment with excellent long-term correction without the risks associated with more extensive surgeries [51]. The treatment for clubfoot is inexpensive, and relatively simple to perform with the Ponseti method of serial casting which avoids the need for surgery. From a global perspective, the Ponseti method has provided opportunity to correct clubfeet in many children in LRIC, where resources for surgical intervention are inadequate or lacking. The key challenges to address are to raise awareness that clubfoot treatable and that treatment is easy and economical.

Slipped capital femoral epiphysis

SCFE is the most common hip disease in adolescence, affecting approximately 0.5 in 1000 children, with a peak incidence of 12 years in girls and 13 years in boys and is more common in certain populations (e.g. Maori children) [52], with being overweight the strongest risk factor [53]. SCFE is more common in boys, but the reported relative risk has varied considerably; in the UK, the male-to-female ratio was 1.7:1 [52]. In SCFE, the slip can be acute, more resembling a fracture, but the vast majority (>90%) are chronic, resulting in a gradually progressing 'cam-like deformity' causing impingement on movement and without intervention, will ultimately lead to early osteoarthritis with pain and disability [54,55]. Late diagnosis is common (median of 6 months from onset) with lack of awareness and appropriate clinical assessment being contributory factors; referred pain to thigh or knee are common and hip examination may be overlooked [56]. Treatment is surgical with the main intention to prevent further slippage. There are principally two different fixation devices – a threaded screw that simultaneously inhibits further growth, or a pin that allows continued growth of the proximal femur; it has recently been shown that continued growth results in a more normal offset of the hip and less risk of persisting deformity in adulthood [57]. The key challenges to address in SCFE are improving access to early surgical intervention, raising awareness to facilitate early diagnosis and preventing/reducing obesity as a major risk factor.

Juvenile idiopathic arthritis

JIA is the most common form of chronic arthritis in childhood [58] with a spectrum of subtypes, clinical profiles and outcomes [59]. Incidence (1.6–23 per 100,000 person-years) and prevalence (3.8–400 per 100,000 person-years) rates vary around the world and between JIA subtypes [60]. Severe JIA subtypes are reported to be more prevalent in Asia, South East Asia (SEA), Latin America and

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Africa [60–63]. Such variation may reflect true racial or disease differences or be influenced by ascertainment or referral bias. Uveitis as a potentially blinding complication of JIA, is common in oligoarticular JIA, which generally has a better prognosis and is more common in studies with predominantly Caucasian children [64]. However, the true prevalence of uveitis in LRIC is likely underestimated due to the unmet need for regular surveillance by ophthalmologists in patients known to have JIA. Untreated or sub-optimally treated JIA results in disability, limitation of growth and psychosocial development and potential visual loss from uveitis [59]. JIA often extends into adulthood with risk of high unemployment, lower mental well-being, bone and joint morbidity (osteoporosis and osteoarthritis) and need for joint replacement surgery [65].

Worse outcomes in JIA are reported in Hispanic, African American and Asian studies [33,66–68], and in countries with low GDP [36]. Such observations have multifactorial explanations, including higher prevalence of poor prognosis subtypes in these populations [68], paucity and poor access to specialist care [5,36,37,69] with delay to diagnosis and inequity being widely reported [5,33,37,69–71]. There have been considerable advances in JIA, including biological therapies, and the condition is now regarded as treatable although many treatments are not always affordable or accessible [3,59]. The use of specialist treatments is facilitated through consensus-based guidelines (invariably developed in HRIC) [3]. A 'window of opportunity' exists and it is quite possible that access to affordable therapies early in disease course is likely to reduce requirements for more expensive care in the long term. The key challenge in JIA is to raise awareness that early diagnosis, access to specialist care and access to treatments will improve the lives for many CYP reduce long-term MSK and visual health burden [59].

Juvenile systemic lupus erythematosus

Juvenile systemic lupus erythematosus (JSLE) is the most common connective disease in children and is life-threatening with no cure. Prevalence and incidence rates of JSLE (3.3–24 per 100,000 children and 0.3–0.9 per 100, 000 children per year, respectively) vary around the world [72] and JSLE is reported to be more common and more severe in Asia, SEA, Latin America and Africa [73–77] compared with the USA and Europe [72,78]. Such variation may be attributed to genetic background, ethnicity as well as ascertainment and selection bias. Organ damage, mostly renal (and also lung, brain and cardiac) is a major cause of morbidity and mortality [79–82]. Many patients with JSLE have ongoing disease into adulthood with significant impact on growth and psychosocial development, education and vocational potential [80,83,84]. There is also a markedly increased risk of cardiovascular disease in adulthood [84,85]. Ten-year survival for JSLE in LRIC and MRIC is approximately 80% [2,80,86–90] compared with 99% in HRIC [85], with lupus nephritis and infection, the major causes of death [91,92].

Early recognition of JSLE with early referral to specialists are integral to better outcomes [93,94]. Diagnosis can be challenging where infections (such as TB) are often mimics of rheumatic diseases and diagnostic capabilities (including availability of autoantibody tests) are often limited in low resource settings [5,95]. Delayed diagnosis and access to specialist care in JSLE with worse clinical outcomes is widely reported across the world [79,88,96–98], often associated with more severe disease activity and organ damage at presentation [75,99,100]. Many of the innovations that have improved survival in HRIC remain unavailable in most of the world [77] and access to renal replacement therapy may be severely limited or non-existent [101]. JSLE recommendations and guidelines to manage JSLE primarily relate to HRIC [4,102] and despite the promising role of novel treatments [84], for patients in many countries, these medicines are not affordable or accessible [5,16,33]. The key challenge in JSLE is to facilitate early diagnosis, access to specialist care and availability of treatments to reduce mortality and morbidity.

Moving forwards – opportunities and solutions

The selected MSK conditions share many challenges; delay in diagnosis (and evidence that early diagnosis and specialist care improve outcomes), poor access to treatments (such as medicines, surgery, physical therapies) and inadequate models of care. The challenges can be extrapolated to the wider spectrum of MSK conditions and are applicable across different healthcare contexts (i.e. not just

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LRIC). Here we discuss opportunities and solutions to address the challenges with focus on raising awareness, preventative strategies, workforce capacity building, models of care and clinical research agendas.

Awareness is key

There remains a lack of awareness about childhood onset MSK diseases; particularly among the public, and healthcare professionals who are often the first point-of-contact for families [103,104]. The importance of a prompt and correct diagnosis, followed by early access to appropriate specialist care and treatment is well documented; however, delays in diagnosis and access to 'right care' remain serious issues [37,105], often relate to lack of awareness and are reported around the world [78,106,107]. However, care must be taken when planning awareness-raising activities to ensure the most appropriate messaging reaches the right target audience or groups of stakeholders, in order to have the highest possible impact. This requires a unified approach led jointly between young people, families and HCPs as partners.

It is important to identify the target audiences (Table 2) and consider the key messages. For example, messaging for CYP, parents (and/or carers) and members of the public will likely focus on:

- Raising awareness that MSK conditions are more common than people think
- The impact on the lives CYP and their families, including education, social life and independence
- The importance of seeking credible healthcare opinion early when there are concerns
- Balancing quality of life and treatment
- Factors that protect and promote MSK health such as lifestyle (e.g. diet, exercise), social cohesion, healthy peer relationships and positive school environments

The messaging is different for policy-makers (and HCPs), where a focus may well be on 'burden', a term which is largely disliked by those living with these conditions. Yet, it is a term which may well be conducive to capturing attention on morbidity, and the cost of disease (*not people*) on health, healthcare systems and the wider economy. It is often the latter approach which levers political and social change at the highest level, reinforced by powerful testimonies and case examples of CYP themselves. Increasing awareness among policy-makers about the impact of MSK conditions on health and well-being as well as national economies will facilitate change in healthcare planning and investment (in the workforce, models of care, access to specialist care and treatment) towards improved outcomes [108].

There is also growing awareness that addressing MSK health will mitigate the burgeoning impact of NCDs (such as cardiovascular disease, dementia and cancer) [9], that interventions need to start in childhood and shift the focus from curative to promotive, preventive and rehabilitative healthcare approaches (http://www.ncdchild.org). Messaging needs to emphasise that many MSK conditions are treatable and that investment to improve access to the right care in CYP will reduce the long-term cost to society. Furthermore, messaging needs to emphasise that MSK specialists are dependent on many other 'non-MSK specialist' HCPs involved in the care pathways that are keys to suspect MSK disease promptly, make an accurate diagnosis and to know when and how to seek specialist opinion [37]. There

Table 2
Target audience groups for awareness-raising activities.

- Children and young people (those with and without MSK diseases)
- Parents, carers and other family members
- Patient and parent organisations and charities
- Members of the public
- Education professionals and academic institutions
- Healthcare professionals across primary and secondary care, across paediatrics, adolescent and adult care, and across disciplines
- Policy-makers, civil servants and politicians
- Global organisations, such as the WHO

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is also an important role for teachers and nursery workers to raise concerns about suspected MSK disease and empower families to seek healthcare [70].

Actions to raise awareness have gathered momentum such as the **World Paediatric Bone and Joint Day** [109] and **World yOung Rheumatic Diseases (WORD) Day** [110] (Fig. 1). Charities and advocacy groups play key roles through a number of mechanisms, including information days for families with HCP input, educating school teams and engaging with the media. Such initiatives help to improve understanding while minimising the stigma for CYP living with these conditions and through clear and open communication, individuals and organisations are inspired to take action. In doing so, changing just one attitude is the step in the right direction; giving families a voice, which can empower them to become advocates in their own communities, encouraging other families to feel less isolated and join a movement campaigning for positive change. When these actions move from isolated events to a global effort then real change can happen with the ultimate goal of giving every child the very best opportunity to live as happy and healthy as possible long into the future. **Wikipedia** as an open e-resource with wide reach to all target audiences; it is important that the entries are up to date and recent efforts have revised the JIA page (https://en.wikipedia.org/wiki/Juvenile_idiopathic_arthritis).

MSK health promotion and addressing road safety

Early intervention is necessary to promote MSK health and needs to involve healthcare, schools, community and society. **Generation Pep** [111] set in Sweden aims to promote physical activity and healthy diet habits targeting families through education and motivational behavioural change. As part of ongoing study, the intervention involves distributed a book at no cost to families of 200,000 5-year olds in 2019 and parents of 2.5-year-old children are given a smartphone application that provides advice towards healthy eating and exercise habits [111]. **The POP study** is a long-term controlled school-based physical activity intervention study with daily exercise at school compared with exercise 1–2 times per week; those with daily exercise attained higher bone mineral content, bone mineral density and greater bone size compared with controls [112]; with gradual reduction in fracture rates, so that the incidence of fracture after 8 years of intervention is less than half of what is expected [113]. Even more interesting, the intervention seems to bestow a more physically active lifestyle even 5–7 years after termination of the intervention [114]. Similar benefit to bone mineral content and were observed in a randomised controlled study (**BONES**) involving dietary advice and weight bearing exercise in young children [115].

Preventing road traffic injuries requires shared commitment at governmental level in multiple sectors, safety features to be included in vehicles, provision of cycle lanes and walkways, transport planning and education. There should also be protecting laws, as exemplified by a mandatory use of bike helmets in some countries as well as safety belts in a cars and buses. Promotion of healthy exercise habits and helping to avoid obesity needs to include provision of open spaces in cities, leisure centres and sport facilities that are affordable and accessible to all levels of physical ability. Addressing obesity is a major challenge at a global level and requires commitment at government levels, policy and laws regarding marketing for foodstuffs and affordable quality food options [24,38].

Workforce capacity building and models of care

Workforce capacity building requires a collaborative, constructive and contextual approach through education and training reaching a breadth of target audiences who have different learning needs. The inadequacy of MSK training for medical school graduates and HCPs has been highlighted [23], especially among primary care physicians and community health workers who may be the first to encounter patients, are crucial to making a diagnosis and instigating referral to specialist care. However, in many parts of the world and especially in LRIC, there is a shortage of HCPs across all grades working in child health to address huge healthcare challenges and with limited resource [32].

Efforts to increase workforce capacity for MSK healthcare therefore have to engage, upskill and support the *existing* workforce at all grades to identify and address their learning needs in a cost-effective pragmatic way with targeted education as well as supporting specialist resource expansion. The level of skills and knowledge will be different depending on roles, healthcare setting and level of

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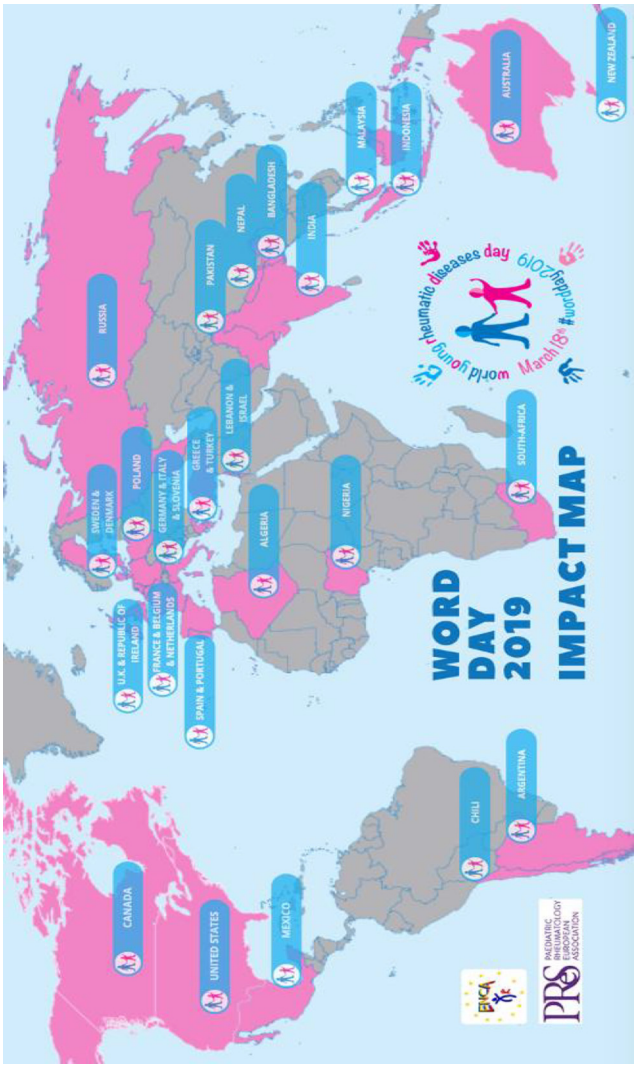

Fig. 1. WORD Day 2019 impact map demonstrating awareness raising activities around the globe.

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expertise needed. Education and training initiatives need to be *contextually relevant in terms of content and format*, *availability, accessibility and affordability.* The Juvenile Arthritis Management in Less-Resourced Countries **(JAMLess)** initiative is the first set of consensus-based recommendations for the management of juvenile arthritis in LRIC and highlights the important of targeted, relevant education and training of the workforce [5]; building the capacity of specialists, researchers and a myriad of HCPs involved in the care of CYP starting with the basics in undergraduate education to different levels of expertise in postgraduate training.

There is need for more paediatric MSK specialists who are integral to clinical service delivery, training and research [5,40,63]; their presence is often the catalyst for change at a local, national and international level providing leadership and advocacy roles [116]. However, specialists cannot function without suitably trained multi-disciplinary teams (MDTs) and providers in the community to enable early diagnosis, prompt referral and sharing clinical care closer to home where possible. Models of care that upskill and support local and community providers with the relevant skills and knowledge to support specialist teams are therefore more likely to be successful and sustainable (Fig. 2).

There are many initiatives to support education and training, but there needs to be an overarching strategy (*addressing scope*, *format*, *reach*, *evaluation*) and clarity about enablers (*including funding*, *resource*, *dissemination*). Reaching out to a wider and non-specialist audience is challenging, but needed in order to upskill and support the existing workforce in the community – family medicine, community workers, paediatricians adult orthopaedic surgeons and adult rheumatologists as well as nurses and allied health professionals all have important roles to facilitate access to right care. However, they have different learning needs based on the clinical context in which they practice; 'one solution does not fit all'.

Table 3 describes example initiatives, their target audiences and impacts where available. Specialist training programmes for paediatric rheumatology (e.g. Paediatric Rheumatology European Society **(PReS) Fellowship Programme**) and orthopaedics are often based in HRIC and while valuable, the experience may be of limited clinical relevance to trainees from low resource settings [5] and who wish to return to their country to practice (e.g. in Africa, Asia or SEA). **The African Paediatric Fellowship Programme** [117] is a different model to develop critical specialist skills for clinicians working in Africa with training delivered 'locally' in South Africa, providing contextually relevant experience and expertise to be of maximal relevance to the 'home' situation. There are other initiatives in LRIC to develop contextually relevant MSK training and curricula for specialists in adult MSK medicine [16,117–119]. **MiracleFeet** (https://www.miraclefeet.org/) is an non-profit organisation working with local partners and providing training, technical and financial resources to create, support and evaluate clubfoot services based on the Ponseti method in LRIC [120]. **RightPath** (www.rightpath.solutions) is a model of MSK triage of CYP in the community by paediatric physiotherapists to identify CYP who can be managed in the community rather than referral for hospital specialist opinion; this model may be of more relevance to HRIC where MSK presentations are common and often relate to self-limiting problems [25].

There is great potential for e-technologies to facilitate education and training using new ways of reaching wider audiences, especially in LRIC, where there is extensive mobile phone network coverage to facilitate communications [121,122]; challenges exist, including reliable internet access, language barriers and enabling learners to adopt new knowledge and skills into clinical practice. There are many existing e-resources and many are already linked to training programmes [116]. For example, paediatric gait arms legs and spine (**pGALS)** is a simple validated MSK assessment [123] widely taught in medical schools worldwide [23], available as a free pGALS app and linked to the **Paediatric Musculoskeletal Matters (PMM)** online information resource [124]; targeting 'non-MSK specialists' and providing foundations for training programmes (e.g. **PReS Basic Course** in paediatric rheumatology). Continuous professional development (CPD) meetings provide networking opportunities to share training models, evidence-based clinical care and research advances. The number of paediatric MSK CPD events and courses in LRIC/MRIC have increased in recent times, making attendance more accessible to resource-limited regions, but financial support to attend such events remains a major barrier for many. Concerns about climate change and the recent coronavirus disease 2019 (COVID-19) pandemic have raised need

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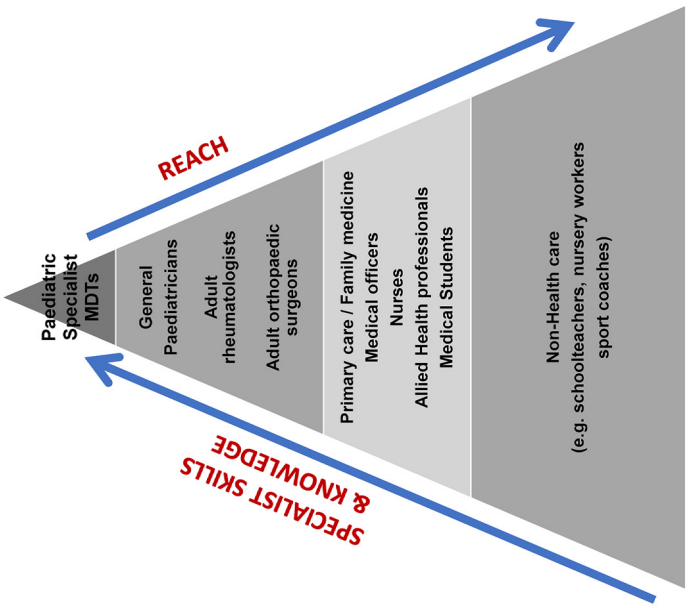

Principles	Strategies	Enablers
'Targeted' Education to fit existing workforce roles	Accessible Affordable Sustainable Relevant Training & CPD	Resources apps websites e-modules e-learning e-networking
Learning outcomes 'fit for purpose'	Inter-professional learning	Mentoring Training programmes

Fig. 2. Workforce capacity building.

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Table 3
Example of Resources, Models of Care and Training in paediatric MSK medicine.

	Model Description	Reach and target audiences	Impact and Outcomes
African Paediatric Fellowship Programme (APFP) [117]	The APFP aims to develop critical specialist skills for physicians working in Africa. This innovative model of training brings post-graduate medical, nursing and allied health trainees from all over Africa to train in various areas of paediatric specialisation using a model that ensures that newly trained specialists continue to deliver care in their home countries.	Training is done in South Africa, providing contextually relevant experience and expertise and trainees, selected based in part on their leadership qualities, are supported in adapting and applying their training and exposure to ensure maximal relevance to their home situation.	Using this model, five paediatric rheumatologists from countries in Africa with no existing specialist expertise available have been trained and are now developing services in their home countries (among more than 100 trained in other disciplines).
JAMLess [5]	Consensus evidence-based recommendation for management of juvenile arthritis in less resourced settings; includes clinical care, education, training, research and advocacy.	Targets clinicians, healthcare planners and training bodies in resource-poor settings.	Developed in Africa, Asia and South America primarily and has transferable value to other regions.
MiracleFeet (https://www.miraclefeet.org/)	MiracleFeet is a non-profit organisation and uses a 'bottom up approach', offering continuous technical and financial support for the treatment of children with clubfoot in LRIC.	Support includes identifying local partners, training healthcare workers and practitioners in the Ponseti method, hiring and training parent educators to increase compliance with treatment, providing treatment supplies, including braces and establishing systems to collect and analyse patient and clinic-level data to monitor quality and measure impact.	International rolling programme in many countries in Africa, Asia and South America. As a cost-effective intervention, MiracleFeet has helped change the lives of more than 44,000 children in 26 different countries [120].
PMM [124] (www.pmmonline.org)	PMM is a free evidence-based online information resource launched in 2014. PMM-Nursing launched 2016. PMM-International (2018) with input of many global partners, includes further content-relevant different healthcare contexts.	Targets a wide audience, including medical students, primary care, general paediatricians, orthopaedic surgeons, nurses and allied health professionals to know about the essentials of paediatric MSK medicine PMM courses (https://cpd.ncl.ac.uk)	Google analytics (April 2020): >500,000 hits, >300 countries and >100,000 users. Supported by e-modules and access to pGALS app. PMM app in pipeline (2020).
pGALS assessment [123]	pGALS is a simple and quick basic MSK assessment and validated in school-aged children and clinical practice. pGALS app (available on apple and google play).	Targets medical students, family medicine, primary care, paediatricians, nurses, allied health to have an approach to MSK examination.	Widely taught in medical schools around the world and has been translated into many languages. Validated in clinical practice in many countries, including LRIC.
PReS EMERGE (EMErging RheumatoloGists and rEsearchers) https://www.pres.eu/activities/young-investigators/about-pres-emerge.html	The PReS EMERGE programme supports training in paediatric rheumatology with clinical and research opportunities.	Young doctors and researchers from all over the world, supported by an experienced faculty and connected online and through social media. The PReS EMERGE fellowship programme funds trainees in paediatric rheumatology	PReS EMERGE supports several programmes, including the fellowship programme, Peer Review Mentoring Programme, Young Investigators Meetings at the annual PReS congress, courses and collaborations with other

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Table 3 (*continued*)

	Model Description	Reach and target audiences	Impact and Outcomes
		to spend up to 6 months in a relevant centre in Europe to gain clinical experience and complete a project.	international consortia to develop shared initiatives
PReS Educational Courses [116]	PReS supports a rolling programme of basic and advanced courses in paediatric rheumatology.	PReS Basic Courses target paediatricians, nurses and allied health and are supported in part by PReS. Advanced courses target specialists and trainees and focussed on skills (e.g. ultrasound) and topics (e.g. JIA, JSLE or autoinflammatory diseases).	Courses have been held around the world (Europe, Africa, Asia and South America). Bursaries from PReS are available to support attendees from LRIC/MRIC.
Project ECHO (https://echo.unm.edu/)	Project ECHO is an exemplar of e-technology to facilitate knowledge mobilisation and empowering the local healthcare providers.	The model connects groups of community providers with specialists at centres of excellence in real-time collaborative interactive sessions. 'Tele-mentoring' with two-way learning; local providers gaining skills and confidence to manage patients closer to home and specialists learning new approaches for applying knowledge across diverse cultural and geographical contexts.	An international initiative based in the US with network hubs in many parts of the world and across medicine. Project ECHO has great potential for wide reach and impact in the context of MSK workforce capacity building and initiatives for CYP are developing (e.g. 'PROMISE' based in India).
RightPath (www.rightpath.solutions)	RIghtPath is a model of care involving MSK triage in the community by paediatric physiotherapists.	Targets primary care and community care to support triage teams with triage guidance and targeted training to identify those CYP who can be managed locally (without specialist hospital referral) and those who do need referral for specialist opinion.	Based in the UK and approximately 25% of referrals can be triaged to be managed in the community rather than referred to hospital specialist care.
WHO EML https://list.essentialmeds.org/	The WHO EML informs countries around the world about the minimum medicine items necessary to meet the most important priority health needs of a population.	The EML informs national medicine lists and health systems to enable safe and effective implementation of therapy in clinical practice; with implications for transportation, storage and handling, staffing and training, care pathways and clinical guidelines.	By 2016, more than 150 countries had developed national lists based on the WHO EML. The need to revise the EML for paediatric rheumatology has been highlighted as the current list does not include 'routine' drugs [6].

for different ways of 'working better together'. This presents a huge opportunity and technology platforms for **e-networking** will undoubtedly continue to grow as an important way to facilitate knowledge sharing and dissemination. **Project ECHO** (https://echo.unm.edu/) is an exemplar learning model using an e-platform to link community local providers and specialists in real-time collaborative interactive training programmes. **Telehealth** uses e-technology to enable clinical care in remote areas with opportunities to upskill and train local providers and studies demonstrate effective Telehealth consultations with a local provider HCP with some MSK experience [125].

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Research and policy agenda

Many of the innovations that have improved outcomes for MSK disease in HRIC remain unavailable in most of the world, but collaborative efforts could have a large impact on the health of many people worldwide [40]. Individuals with MSK disease from LRIC are under-represented in research; this disparity is even worse in CYP with MSK disease, despite 90% of the world's CYP living in low resource settings [16,72,126]. People from these regions have little or no part in the development of research questions and their experience of living with MSK diseases is poorly represented [127].

The impact of financial, political, social or environmental factors on the opportunity to conduct clinical, epidemiological, educational as well as basic and translational research create major challenges worldwide [40,108]. At an international level, action is needed to mandate pharmaceutical and technical companies and all stakeholders including patients, to come together to develop and fund-relevant and contextually appropriate clinical research questions and studies that are more generalisable to different populations and settings [23]. International collaborations with better funded and powerful international industry and academic partners need to very carefully balance the benefit and potential risk to local patients. There is need for research governance and policy to address data safety and patient privacy, share data freely and aim to build locally led research capacity, especially in LRIC, and perform research with a clear aim to benefit local patients and inform the global community. International policy and stakeholder collaboration needs to leverage pricing and distribution challenges to increase the availability and accessibility of medicines and treatments with greater equity. Workforce capacity building and clinical care delivery are inexorably linked; academic, clinical and patient partners need to leverage healthcare planners at a national level to resource more training programmes 'fit for purpose' to implement and sustain new models of care. Key themes and how these can be achieved are summarised as follows:

- There is an urgent need to document epidemiology and unique phenotype of MSK disease in LRIC in order to advocate for local care and policy development. Data from LRIC serve as a globally valuable potential source of information with diverse, unique genetic backgrounds and high burden of infectious diseases, which influence disease phenotypes and management approaches. There is much to learn that will benefit knowledge and understanding across all settings and without research, patients in low resource settings will remain invisible, undiagnosed and inadequately managed.
- Research capacity building is dependent on having a local workforce trained in paediatric rheumatology and research methods to facilitate grant success and high impact publications. The Paediatric Update on Lupus in South Africa (PULSE) cohort [1], was an international collaboration and provided the first profile of JSLE in an African cohort demonstrating higher rates of catastrophic disease (blindness, stroke, renal failure), higher rates of nephritis and severe cardiovascular manifestations when compared with the US [2]. This valuable data enabled local units to advocate better care for CYP with SLE, targeted education locally to HCPs and provided preliminary data to leverage future research funds.
- There is need for clinical trials to include LRIC settings to address safety and efficacy and consider protocols to include less costly interventions. In terms of drug development and clinical trials, many are highly targeted agents that are not tested with rigour in LRIC settings, with the high burden of infection and invariably are too expensive and inaccessible for use in clinical practice.
- Inventive and novel drug development is needed. LRIC have the unique opportunity to be creative, find new approaches, which are appropriate, affordable and sustainable to local settings. Many LRIC have well-funded research units working on infectious disease, with excellent immunology and basic science expertise. Utilising this local expertise to develop collaborative, cross platform, novel and creative research questions and hypotheses is vital. Drug repurposing is an example, where pathways that are proven to be beneficial elsewhere may be targeted with existing drugs, with better safety profiles and highly decreased development time and costs.
- Policy based on consensus and evidence-based recommendations, standards of care and treatment guidelines for clinical care are important to leverage better care for patients [3,4] but are not always of relevance to resource-poor settings. The JAMLess initiative provided the first recommendations

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relevant to LRIC with limited access to medicines and high background burden of infections [5] and serve as a model for other parts of the world [6].

- The WHO EML is important to influence and inform national formularies, especially in LRIC. The current EML for children needs to be revised to include further relatively cheap medications, such as intra-articular corticosteroids and needs greater clarity to access medicines (such as methotrexate and other traditional medicines used in paediatric rheumatology). Application for such revision to the EML is in progress and likely to have considerable impact around the world.
- Expansion of models of care are required to address 'local' need. At a national level, stakeholders can use standards to benchmark 'state of play' and inform resource allocation to support and sustain models of care. We can learn much from existing models of care (Table 3). Stakeholders need to come together, think innovatively to modify existing models to address unmet need, consider the workforce implications and set relevant metrics to evaluate implementation on clinical care and patient outcomes.
- Workforce capacity building will be informed by benchmarking using standards of care and human resource need to implement models of care. Healthcare planners need to work in partnership with clinicians, training bodies and academic institutions. For example, the successful MiracleFeet model could be expanded to include the 'essentials of MSK medicine' beyond clubfoot given the similar target audiences working in low resource settings with high levels of unmet MSK need. Upskilling and supporting the workforce to acquire the skills and knowledge for their various roles in clinical care (Fig. 2) requires commitment and investment at a national level in partnership with all stakeholders, including healthcare planners, clinicians and training institutions.
- The role of e-technologies in models of care, education and training has huge potential to expand with wide reach to include low resource settings [7]. Healthcare planning policy at an international- and national-level needs to encompass global technology and communication industries with commitment to invest and grow capacity to improve health for all.
- Patients and families need information about conditions and treatments that is high quality and evidence based. Healthcare providers, policy-makers, non-profit organisations and patient organisations need to work together and commit to create and curate resources with open and equitable access.

Summary – 'our call to action'

'If you want to go fast, go alone. If you want to go far, go together' – African proverb

With greater awareness and collaboration to harness existing and emerging technical advances, knowledge and innovations, we have huge opportunity to advance to make real impact and achieve 'better MSK health for all'. The challenges are daunting, and in some cases, appear insurmountable, but failure to confront them ensures that the burden of MSK disease in CYP will significantly reduce quality of life for millions of people. Inter-disciplinary and cross-sectional collaborative efforts, extending beyond the remit of individual healthcare providers and countries, is crucial. Using the tools and opportunities offered by the 'fourth industrial revolution', the effort to 'improve MSK health for all' can be energised through sharing of novel ideas and 'working better together'. By breaking out of silos, we can transfer skills, knowledge, models of care and education to engineer change in society and to optimise impact on a wider scale – 'stay local, think global'.

Disclaimer

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