

ORIGINAL PAPER

## Universal Health Coverage “Leave No Child Behind”

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### ABSTRACT

**Aim of the study:** Multiple stakeholders are involved in achieving Universal Health Coverage (UHC) as part of the Sustainable Development Goals (SDG). The estimated more than 90 million children with disabilities are among the most vulnerable members of the world's population. Paediatricians around the world have united to promote a world where all children, regardless of their abilities or disabilities, can enjoy a healthy life and well-being. We examined: “What would be the least paediatricians could do to contribute to the UHC?”

**Material and methods:** In a cross-sectional study, paediatricians engaged in care for children with disabling and rare conditions were questioned on 8 of the UHC statements concerning child health, primary care services, availability and affordability of diagnostics and therapies and digital health, as well as country of residence and level of practice.

**Results:** The responders were from Europe and Israel, Asia, and the US practicing at primary-, secondary-, and tertiary care levels in high and middle economy countries. Promotion of paediatric primary care could reduce mortality and morbidity, according to 39/48 (81%) respondents. An active role of paediatricians in providing quality information would increase access to health services for children with disabilities, according to 40/48 (83%) responders. Improved data exchange is necessary to deliver primary care as a cornerstone, according to 38/48 (79%) responders. Respondents practising in middle-economy countries reported significantly more frequently than their colleagues in high economies countries about “out of pocket” payments for diagnostics and therapies as well as reduced availability. In order to increase global awareness and international solidarity, a panel of participants in a paediatric network felt that paediatricians should undertake necessary actions to support the achievement of UHC.

**Conclusions:** The economic gap in diagnostic and therapeutic facilities in paediatric practice should be considered in achieving UHC. An international paediatric network should support achieving the UHC by providing adequate paediatric training and quality (digital) information.

### KEY WORDS:

**Universal Health Coverage, child health, disabled, rare disease, eHealth.**

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## WHAT IS KNOWN

- The United Nations endorsed a declaration on UHC.
- Primary care is considered the most cost-effective way to ensure access to essential health.

## WHAT IS NEW

- The gap in affordability and availability of diagnostic facilities and therapies between high-economy countries versus middle-economy countries must be addressed to provide UHC in childhood and youth.
- Harmonization of technology is needed to enable high-quality communication and sustainable digital child health systems to reach UHC.

## INTRODUCTION

Universal Health Coverage (UHC) [1], endorsed by the United Nations in September 2019, means that all people and communities could use the promotive, preventive, curative, rehabilitative and palliative health services they need of sufficient quality, to be effective, whilst also ensuring that the use of these services does not expose the user to financial hardship. UHC should be based on strong people-centred primary health care (PHC) reaching the poor, vulnerable, and marginalized individuals in society. Approximately 100 million people are still being pushed into extreme poverty because they have to spend on health care [2]. Managing chronic diseases and responding to outbreaks of infectious diseases require collaborative action at different levels of the health system and across multiple stakeholders. To achieve the Sustainable Development Goals (SDG) by 2030, the rate of decline in prevalence of child mortality among children younger than 5 years of age needs to accelerate considerably compared with progress made since 2000 [3]. Health systems have a fundamental responsibility and obligation to engage with patients, their families, local communities, as well as a range of stakeholders, partners and sectors. UHC will not be achieved until health systems and their diverse stakeholders are ready to engage with each other in effective ways [4]. Large inequities in health systems and economies exist between and within countries. Countries should implement the World Health Organization's guidance on UHC and primary health care governance, financing, health workforce, equity, and quality of care, among others. There is general agreement that it is critical to include chronic conditions in PHC; in order to do so, policymakers must refine domestic and international financing patterns and explore innovative solutions [5]. Children with disabling and rare conditions are among the most vulnerable and marginalized of the world's population. The European Academy of Paediatrics (EAP) established a network of paediatricians engaged in the care of such children in Europe and beyond. In this study, we

explored how paediatricians could contribute to different facets of UHC by questioning this paediatric network on the UHC declaration addressing the health and well-being of children, with emphasis on children with a disability. What would be the least paediatricians could do to contribute to the UHC? What factors related to economy, training, and practice, as experienced by paediatricians from different countries, need to be addressed to achieve UHC? What innovative solutions could support implementation of UHC for children in Europe and beyond?

## MATERIAL AND METHODS

A structured questionnaire titled "Universal Health Coverage, leave no child behind" was designed, based on experience gained from international collaboration on care for children with rare and/or disabling conditions. Three questions defined the responders by the following: country of residence (A), practicing medical specialty (B), and the level of practice common in paediatrics – primary (community) care, secondary (hospital) care, and tertiary (university hospital) care (C). Seven questions were related to the UHC Political Declaration [1] statements numbers 13, 29, 31, 34, 37, 46, 50, and 78 (Supplement) to child health and care for the disabled. A panel of 80 internationally engaged paediatricians identified through the paediatric network, including members of the EAP as well as members of the European Paediatric Association, European Confederation of Primary Care Paediatricians, and the Rare Disease Forum of the Sri Lanka College of Paediatricians, were invited to respond using a survey through SurveyMonkey. The panel members were living in Europe and Israel (73), in Asia (5), and in the US (2). Responses were collected from October 2019 to June 2020. The non-response bias may occur because of technical reasons, no time or interest in surveys, no affiliation with the subject, and other unknown factors.

Statistical analyses were performed by  $\chi^2$  tests to compare the subgroup of participants, according to country of practice by the economy (A) and care setting (B, C) of the respondents as variables. A cut-off point of  $p < 0.05$  was used.

## RESULTS

The response rate was 48/80 (60%). The responders were grouped by the following: A) The country of practice classified according to their status of economy as defined by the World Bank in the fiscal year 2020 [6]: *High economy (HE)*: Austria, Belgium, Croatia, Estonia, Finland, Germany, Greece, Hungary, Ireland, Israel, Italy, Lithuania, the Netherlands, Poland, Portugal, Slovenia, Switzerland, the USA, and the United Kingdom (19 countries,  $n = 32$ ); *Upper-Middle economy (MH)*: Armenia, Bosnia & Herzegovina, Bulgaria, Georgia, North-Macedonia, Russia Federation, and Sri Lanka (7 countries,  $n = 10$ );

**TABLE 1. UHC#29 To reduce mortality and morbidity, by respondent's level of paediatric care practice and country's economy**

n = 48	Primary (12)	Secondary (7)	Tertiary (25)	Trainee/Other (4)	HE (32)	MH/ML (16)	Total (48)
Health schemes	6 (50%)	7 (100%)	19 (76%)	4 (100%)	21 (66%)	15 (94%)	36 (75%)
Primary care	10 (83%)	5 (71%)	20 (80%)	4 (100%)	25 (78%)	14 (87,5%)	39 (81%)
Digital health	4 (33%)	4 (57%)	12 (48%)	4 (100%)	16 (50%)	8 (50%)	24 (50%)
P-value				0.846788		0.783815	
$\chi^2$				1.3851		0.4872	

A  $\chi^2$  test showed that neither level of practice nor the country's economy was related to the responders' answers to opinion questions

*Lower-Middle economy (ML):* India, Moldova, and Ukraine (3 countries, n = 6). Paediatricians in *Low economy* countries were not included. B) The medical specialties were as follows: 44 respondents were paediatricians, 2 were trainees in paediatrics, and 2 were medical geneticists. C) The care setting of respondents defined by work in primary (ambulatory) care n = 12, secondary (hospital) care n = 7, tertiary (university hospital) care n = 25, or 'other': 2 as trainees and 2 indicated another position.

**RESPONSES RELATED TO UHC STATEMENTS**

In the order of the questionnaire:

UHC#29: "In your opinion, what would be necessary to reduce mortality and morbidity? Answers (multiple choice): 1) Improved efficiency of preventive child healthcare schemes 36/48 (75%); 2) Promotion of paediatric primary care 39/48 (81%); 3) Improved integration of digital health information 24/48 (50%) (Table 1).

UHC#13 and #46: In your opinion, what would be necessary to **deliver primary care as a cornerstone?** Answers (multiple choice): 1) Additional paediatric health and social care training for primary health care providers 40/48 (83%); 2) Open-source quality information 23/48 (48%); 3) Involvement of family 26/48 (54%); 4) Improved data exchange between families, primary care, and other levels of care 38/48 (79%) (Table 2: Deliver primary care as a cornerstone by 44 respondents working in paediatric practice: primary, secondary or tertiary care, excluded responding trainees and 'others').

UHC#50: **Availability, affordability, and efficiency of health products in my country:** Answers (multiple choice): 1) Diagnostics are fully covered 24/43 (56%); 2) Diagnostics are restricted by ability to pay 16/43 (37%); 3) Novel diagnostics are not available 7/43 (16%); 4) Treatments are fully covered 20/43 (47%); 5) Treatments are restricted by ability to pay 19/43 (44%); 6) Novel therapies are not available 7/43 (16%) (Table 3).

UHC#37: In your opinion, what is necessary to **increase health services to all persons with disabilities?** Answers (multiple choice): 1) Paediatricians should play an active role in providing quality information regarding the cause of disabilities 83% (40/48); 2) Disabilities may be caused by an undiagnosed rare condition 34/48 (71%); 3) Families with a disabled child become isolated from so-

**TABLE 2. Deliver primary care as a cornerstone by 44 respondents working in paediatric practice: primary, secondary or tertiary care, excluded responding trainees and 'others'**

n = 44	Primary (12)	Secondary (7)	Tertiary (25)	Total (44)
Training	10 (83%)	5 (71%)	21 (84%)	36 (82%)
Information	5 (42%)	6 (86%)	10 (40%)	21 (48%)
Family	5 (42%)	4 (57%)	14 (56%)	23 (52%)
Data exchange	8 (67%)	6 (86%)	20 (80%)	34 (77%)
P-value	0.894134			
$\chi^2$	2.2616			

The  $\chi^2$  shows there is no relationship between the level of practice of the responders and the answers to the opinion questions.

**TABLE 3. UHC#50: Availability and affordability of diagnostics and therapies by country by health economy according to the World Bank (2020)**

n/%	HE (28)	MH / ML (15)	Total (43)
<b>Diagnostics</b>			
Diagnostics covered	22 (79%)	2 (13%)	24 (56%)
Diagnostics restricted by payment	3 (13%)	13 (87%)	16 (37%)
Diagnostics not available	1 (3,6%)	6 (40%)	7 (16%)
P-value			< 0.00001
$\chi^2$			26.2533
<b>Therapies</b>			
Therapies covered	18 (64%)	2 (22%)	20 (47%)
Therapies restricted by payment	8 (29%)	11 (56%)	19 (44%)
Therapies not available	2 (7%)	5 (44%)	7 (16%)
P-value			0.001504
$\chi^2$			12.9998

ciety 24/48 (50%); 4) Disabled children have high-quality care in my country/state 17/48 (35%); 5) Families are empowered and do not need (paediatric) support 1/48 (2%).

UHC#34: What is necessary, in your opinion, to **strengthen efforts on rare diseases?**

Answers (multiple choice): 1) Accessible diagnostics, regardless of the ability to pay 41/46 (89%); 2) Accessible

treatment without exposure to financial hardship 35/46 (78%); 3) Wealthier economies to support middle and lower economies 25/46 (57%).

UHC#31: At present, do you use an **electronic system for vaccination data**? Answers (one choice): 1) No, we have paper registration 18/48 (37.5%); 2) Yes, we have electronic registration 18/48 (37.5%); 3) Yes, we have an electronic system that can exchange data with other systems 1/48 (2%); 4) Yes, we have an electronic system including the (WHO) ATC classification to sustain universal data exchange 3/48 (6%); 5) I do not know 6/48 (12.5%).

UHC#78: **To increase global awareness, paediatricians could:** Answers (multiple choice): 1) Establish a global paediatric network to support the SDGs of the UHC 42/48 (87.5%); 2) Support primary paediatric care with an emphasis on care in rural and distant areas 39/48 (81%); 3) Identify the specific needs of poor and vulnerable children 34/48 (71%); 4) Engage in high-quality, affordable, sustainable, and semantic digital child health 33/48 (69%); 5) Support families in their fundamental needs 32/48 (67%); 6) No actions are necessary 0/48 (0%).

## DISCUSSION

With the endorsement of the UHC, there is an opportunity to focus on high-level consensus on translation into meaningful actions leaving no child behind. Inequities in health systems and economies, as experienced by paediatricians, have to be considered. To reach the UHC, training health workers to provide quality child-centred care is of high priority, as well as policymakers committed to investing in the UHC. In the following thematic paragraphs, some practical issues and actions are discussed.

### PAEDIATRIC WORKFORCE

Primary paediatric care, defined as general paediatric care, first access care, preventive care, health education, community care, rehabilitative care, and coordination of all care givers, was practiced in 52% of European countries in 2012 [7]. In our survey 81% of the responders in high and middle economies shared the opinion that promotion of paediatric primary care would reduce maternal and child morbidity and mortality in the frame of UHC#29 (Table 1). Eighty-two per cent of all practicing paediatricians, agree that additional paediatric health and social care training in primary health care is necessary to deliver primary care as a cornerstone, UHC#13 and #46 (Table 2). Effective health coverage incorporates not only receipt of services but also their quality [8]. It is acknowledged that there is a need to reassess the training of all health care professionals caring for children, ensuring the support of new models of integrated and multidisciplinary care and focusing on the needs of the child and the family [9]. Moving towards preventive and primary child health services by well-trained multidisciplinary

teams of caregivers, such as nurse practitioners, family physicians, physiotherapists, speech therapists and psychologists and coordinated by paediatricians [7] is in line with the 2019 UHC directive.

### COVERAGE OF DIAGNOSTIC TESTS AND TREATMENT

The share of out-of-pocket expenditure in overall health spending has been consistently declining across all income groups since 2000 [5]. We find that respondents from middle-economy (MH/ML) countries reported about “out of pocket” payments for diagnostics and therapies, as well as reduced availability, significantly more often as opposed to their colleagues practicing in HE countries (Table 3). This 2-fold gap in affordability and availability between HE and middle-economy (MH/ML) countries has quality and economic consequences that have to be addressed to achieve UHC#50. Novel diagnostics, as targeted gene panels, become relevant in the diagnostic pathway, with greatly improved cost and benefit [10, 11]. Some examples: Chronic renal disease may continue to remain of unknown origin in countries where gene panels are not available or affordable. To define the diagnosis of progressive renal diseases gene panel tests should be available to assure adequate care. Currently, genetic testing is recommended before performing renal biopsy, because it is a non-invasive technique. In countries such as North Macedonia and Sri Lanka, the latter with a high incidence of chronic kidney disease of unknown aetiology [12], these gene panels are not available. Genetic testing may be cost effective by substituting for numerous traditional tests and hospital admissions. Palmer *et al.* [13] demonstrated an integrated diagnostic pathway for children with epileptic encephalopathy, with both clinical utility and cost effectiveness. In Australia, a child with global developmental delay is best served by early recognition in ambulatory paediatrics with opportunities to have genetic sequencing before an extensive diagnostic process typically involving clinical assessment and multiple investigations [14]. While in contrast, many African nations lack the resources to provide care and follow-up on morbidity and mortality of children with chronic conditions. Reliable data are sparse, and the mortality rate of children under 5 years old due to sickle cell disease is estimated to be over 50% [15, 16]. Paediatricians confirm the urgent need for global efforts to level the availability, affordability, and efficiency of health products, UHC#50.

### DISABLING AND RARE CONDITIONS

Developmental disabilities, and hearing and visual impairments may well be features of an undiagnosed rare condition. Unfortunately, in many societies misconceptions reign. Without understanding the natural

causes, disabled children are hidden from society or abandoned in hospitals or foster care. Most responders (83%) agree that paediatricians play an active role in providing quality information on the cause of disabilities contributing to UHC#37. Knowing the aetiological diagnosis leads to understanding associated health risks and disabilities. To strengthen efforts on rare diseases, UHC#34, accessibility of diagnostics, regardless of the ability to pay, is a requisite according to 89% of respondents. Gains in UHC should be made by improving health system efficiency [17]. Vulnerable populations, such as disabled children growing up in poor families living in rural areas, might be left behind without access to health coverage unless deliberate efforts by stakeholders are made to reach them.

#### E-HEALTH SUPPORTING UNIVERSAL HEALTH COVERAGE

Digital technologies introduce novel opportunities to address health system challenges, and thereby offer the potential to enhance the coverage and quality of health practices and services. The WHO launched a guideline with recommendations based on a critical evaluation of the evidence on emerging digital health interventions that contribute to health system improvements [18]. To strengthen public health surveillance and data systems, UHC#31, a digital approach to child health care, including vaccination, growth, and development registration, is feasible. To deliver primary care as a cornerstone, UHC#13 and #46, 79% of all responders indicated that it is necessary to improve data exchange between families, primary care, and other levels of care. However, at present, paper registrations of vaccination are still in use by 37.5% of the responders of our survey both in HE and middle-economy (MH/ML) countries. Together, standards such as the International Classification of Disease of the WHO, the Logical Observation Identifiers Names and Codes (LOINC), the Anatomical Therapeutic Chemical (ATC) of the WHO, and International Classification of Functioning, Disability, and Health of the WHO provide vocabularies to describe and relate diagnostics, medical conditions, medicines and vaccinations, health, and well-being in electronic health record systems and exchanged by Fast Healthcare Interoperability Resources. In the case of a pandemic, integrating LOINC codes, as for SARS-CoV-2, may contribute to understanding the relationship between the clinical spectrum of corona virus disease 2019 and the effectiveness of vaccines. To accomplish interoperability of health-related data between health care providers and personal health records held by clients, patients, or care-takers, global actions to strengthen digital (child) health systems, sharing coverage of international standards, should be prioritized [19-21].

## CONCLUSIONS

In order to increase global awareness and international solidarity, UHC#78, a panel of participants in a European rare disease paediatric network felt that promotion of paediatric primary care would reduce child morbidity and mortality. Due to the lack of affordability and availability of diagnostic facilities and therapies in middle- let alone lower-economy countries, chronically ill and disabled children are deprived of accurate diagnosis or proper therapy. Unless deliberate efforts are made to reach these children, they face preventable morbidity and death without having a chance to profit from advances in medical and digital science. The implementation of a sustainable digital child health system, in line with the WHO recommendations on digital health as well as the UHC, requires the support of policymakers. Further research should include identification of more specific actions: "to support primary paediatric care with an emphasis on care in rural and distant areas and support of the specific needs of chronically ill and disabled children".

## LIMITATIONS

The individual approach of engaged international active paediatricians limits the cohort size. Paediatricians in low-economy countries were not included. An explorative, non-validated questionnaire was used. Possibly not all options of paediatric contributions were addressed. More qualitative studies and in-depth analysis of opinions and comments given in the questionnaire may define more specific contributions of paediatricians to the UHC.

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## DISCLOSURE

The authors declare no conflict of interest.

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