Universal Health Coverage "Leave No Child Behind "

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Abstract

Purpose: Multiple stakeholders are involved in achieving Universal Health Coverage (UHC) as part of the Sustainable Development Goals (SDG). The estimated over 90 million children with disabilities are among the most vulnerable members of the world's population. We questioned :'What would be the least paediatricians could do to contribute to the UHC?'

Methods: In a cross sectional study an international network of paediatricians engaged in children with disabling and rare conditions was questioned on eight of the UHC statements regarding child health in relation to primary care services, availability and affordability of diagnostics and therapies as well as digital health.

Results: Promotion of paediatric primary care could reduce mortality and morbidity according to 39/48 (81%) respondents. Pediatricians could play an active role providing quality information to increase access to health services for children with disabilities stated 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 significant more frequently than their colleagues in high economies countries about "out of pocket" payments for diagnostics and therapies as well as reduced availability. All respondents agreed that taking no action to support the achievement of UHC, is not an option.

Conclusion: 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.

Keywords

Universal Health Coverage; child health; disabled; rare disease; eHealth; exome screening

What is known

- 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.

Background

Universal Health Coverage (UHC)[1] 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-centered primary health care 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 for 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 realize the Sustainable Development Goals (SDGs) by 2030, the rate of decline in prevalence of child mortality among children younger than five years of age needs to accelerate considerably compared with progress made since 2000[3]. UHC can be achieved when diverse stakeholders are ready to engage with each other in effective ways [4]. Large inequities remain between and within countries. Progress is particularly slow in improving access to skilled health workers and essential medicines[5]. Children with disabling and/or rare conditions are among the most vulnerable and marginalized of the world's population. The European Academy of Pediatrics (EAP) established a network of paediatricians engaged in the care for such children in Europe and beyond. In this study, we explored how paediatricians could contribute to different facets of UHC by questioning a panel of paediatricians on the UHC declaration addressing health and well-being of children, with emphasis on children with a disability. The objective of the study was: 'What would be the least paediatricians could do to contribute to the UHC?'

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: country of residence (A), practicing medical specialty (B) and the level of practice common in paediatrics: primary (ambulatory) care, secondary (hospital) care, tertiary (university hospital) care (C). Seven questions relate 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 pediatric 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 on a survey through SurveyMonkey. The panel members were living in Europe and Israel (73), in Asia (five) and in the US (two). 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-square tests to compare the subgroup of participants, according to country's of practice by 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 grouped by: A) The country of practice classified according to their status of economy as defined by the World Bank in Fiscal year 2020[6] : *High economy (HE)*: Austria; Belgium; Croatia; Estonia; Finland; Germany; Greece; Hungary; Ireland; Israel; Italy; Lithuania; Netherlands; Poland; Portugal; Slovenia; Switzerland; USA; United Kingdom (19 countries) n = 32; *Upper-Middle economy (MH):* Armenia*;* Bosnia & Herzegovina; Bulgaria; Georgia; North-Macedonia; Russia Federation; Sri Lanka; (7 countries) n = 10 ; *Lower-Middle economy (ML):* India; Moldova; Ukraine (3 countries) n = 6. B) The medical specialty: 44 respondents are paediatricians, two trainees in paediatrics and two 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': two as trainees and two 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)

Table 1 UHC#29 To reduce mortality and morbidity, by respondents level of pediatric care practice and countries economy

N=48	Primary (12)	Secondary (7)	Tertiary (25)	Trainee/ Other (4)	HE (32)	MH/ML (16)	Total (48)
Health schemes	6	7	19	4	21	15	36 (75%)
Primary care	10	5	20	4	25	14	39 (81%)
Digital health	4	4	12	4	16	8	24 (50%)
p-value				.846788		.783815	
$\chi 2$				1.3851		.4872	

A chi-square test showed that neither level of practice nor the country's economy was related to the responders' answers to opinion questions

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)

Table 2 UHC#13 and UHC#46 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	5	21	36(82%)
Information	5	6	10	21(48%)
Family	5	4	14	23(52%)
Data exchange	8	6	20	34(77%)
p-value				.894134
$\chi 2$				2.2616

The chi-square shows there is no relationship between the level of practice of the responders and the answers to the opinion questions.

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)

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

	n/%	HE (28)	MH/ML (15)	Total (43)
Diagnostics	Diag Cov	22 (79%)	2 (13%)	24(56%)
	Diag Rest	3 (13%)	13 (87%)	16(37%)
	Diag NA	1 (3,6%)	6 (40%)	7(16%)
p-value				<.00001
$\chi 2$				26.2533
Therapies	Ther Cov	18 (64%)	2 (22%)	20(47%)
	Ther Rest	8 (29%)	11 (56%)	19(44%)
	Ther NA	2 (7%)	5 (44%)	7(16%)
p-value				.001504
$\chi 2$				12.9998

Legend: Diag= Diagnostics, Ther= Therapies, Cov=Covered, Rest= Restricted by payment, NA= Not available

Diag The chi-square statistic is 26.2533. The p-value is < 0.00001. The result is significant at p <.05.
Ther The chi-square statistic is 12.9998. The p-value is .001504. The result is significant at p <.05.

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 society 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 which 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

To reach the goals of the UHC, trained health workers providing quality people-centred care are of high priority; as well as policy-makers committed to investing in UHC. 'What would be the least paediatricians could do to contribute to the UHC?' The results are discussed in the following thematic paragraphs.

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, independent of their level of practice or country's economy, as defined by the Wold Bank, share the opinion that promotion of paediatric primary care would reduce maternal and child morbidity and mortality and increase access to quality health-care services for newborns, infants and children, in the frame of UHC#29 (Table 1). 82% of the responding 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 focuses 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 pediatricians[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 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 two-fold gap on affordability and availability between HE and MH/ML countries has quality and economic consequences and 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, since 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 pediatrics 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 five 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, 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 pediatricians have 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 according to 89% of respondents a requisite. 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 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 are contributing 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 improved 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 HM/LM countries. Three respondents reported the implementation of the (WHO) ATC (Anatomical Therapeutic Chemical) classification for vaccination in their digital health system. Together, standards as International Classification of Disease (WHO), the Logical Observation Identifiers Names and Codes (LOINC) and the ATC provide vocabularies to describe and relate diagnostics, medical conditions and treatment in electronic health record systems and exchanged by Fast Healthcare Interoperability Resources. In case of a pandemic integrating LOINC codes, as for SARS-CoV-2 commercial in vitro diagnostics, may contribute to understanding the relation of 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 record's held by clients/patients or care-takers, digital health systems must share coverage of standards[19, 20, 21].

Conclusions

In order to increase global awareness and international solidarity, UHC#78, a panel of participants in an European rare disease paediatric network felt that paediatricians should undertake necessary actions. Due to the lack of affordability and availability of diagnostic facilities and therapies in middle economy countries, chronically ill and disabled children are deprived of receiving 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. By supporting high quality communication between primary and other levels of care and harmonizing technology, it would be feasible to create a sustainable digital child health system, in line with the WHO recommendations on digital health. For the interpretation of the results, more extensive ideas and solutions would be achieved by reaching out to colleagues actually working in community care with the aim: "to support primary pediatric care with an emphasis on care in rural and distant areas and support the specific needs of chronically ill and disabled children".

Limitation

The individual approach of engaged international active paediatricians is limiting cohort size. An explorative, not-validated questionnaire was used. Possibly not all options of paediatric contributions have been addressed. More qualitative studies and in depth analysis of opinions and comments given in the questionnaire may define more specific contributions of pediatricians to the UHC.

Abbreviations

ATC: Anatomical Therapeutic Chemical
EAP: European Academy of Paediatrics
EHR: Electronic Health Records
GP: General Practitioner
HE: High Economy
LOINC: Logical Observation Identifiers Names and Codes
MH: Middle High Economy
ML: Middle Low Economy
SARS-CoV-2: Severe acute respiratory syndrome coronavirus 2

SDG: Sustainable Development Goals
SCD: Sickle Cell Disease
UHC: Universal Health Coverage
UN: United Nations
WHO: World Health Organization

Declarations

Ethics approval and consent to participate: This article does not contain any invasive studies with human participants or animals performed by any of the authors.

Consent for publication: the manuscript does not contains any individual person's data in any form

Availability of data and materials: The data sets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

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The study conception and design has been possible by the work of the paediatric rare disease network.

Specific topics and contributions of the authors: LS Material preparation, data collection, statistics and data analysis; DN Neurology and Rare Diseases; data analysis and manuscript; AB Childhood disabilities ; PA Primary Care and eHealth; LM Rare Diseases in Middle Economy country; SC Data analysis and manuscript; SL General paediatrics and manuscript; AM Child Health and Manuscript; PA Manuscript; JvG Data analysis; ZG Rare Diseases and data analysis; VT Renal and Rare Diseases and data analysis.

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