

# Universal Health Coverage, Leave no child behind

## Introduction

Following their high-level meeting on 23 September 2019, world leaders of the United Nations General Assembly made a Political Declaration on Universal Health Coverage (UHC). UHC ensures all people, everywhere, can access the quality health services they need without facing financial hardship. “This declaration represents a landmark for global health and development,” said Dr Tedros Adhanom Ghebreyesus, Director-General at WHO. “*The world has 11 years left to make good on its sustainable development goals. Universal health coverage is key to ensuring that happens.*”

The Declaration reaffirms:

- the right of every human, without distinction of any kind to the enjoyment of the highest attainable standard of physical and mental health, and
- the 2030 agenda on Sustainable Development Goals with a view to **leaving no one behind** and **reaching the furthest behind first**.

During October – November 2019 a survey was conducted among the European Paediatric Network (members of European Academy Paediatrics, European Paediatric Association and the European Confederation of Primary Care Paediatricians). Questions relate to several paragraphs of the Political Declaration addressing child health including disabled children.

‘What would be the least paediatricians can do to contribute to the UHC?’

## **Reaching the furthest behind first**

### - The importance of primary care

The most powerful aspect is the importance of primary care, as emphasized in the Declaration. From the first question regarding measures to reduce maternal, neonatal, infant, and child mortality and morbidity, the promotion of primary care arises as a key issue. A large number of respondents highlight the importance of supporting “primary paediatric care with an emphasis on care in rural and distant areas...” This is particularly applicable to *reaching the furthest behind first*.

### - The disabled child

To “increase access to health services to all persons with disabilities...” a large proportion of the responders indicate; “paediatricians should take an active role in providing quality information on the cause of disabilities”. Suggestions to improve services:

- an effective integrated medical and social approach
- collaboration between health and social services at the primary care level
- better coordination of services

## **Leaving no one behind**

### - Diagnosis

Respondents agreed that accessible diagnostics, regardless of ability to pay, were essential, and offered suggestions to relieve costly genetic tests and patient diagnostic odyssey in rare disease:

- open source information to improve knowledge of medical care taker
- unification of diagnosis and treatment at the European level, increasing patient numbers to improve systems efficiency and cost-effectiveness

### - Digital Health

Improved integration of digital health information would aid collaboration and enable services to be better coordinated; this was acknowledged in the survey, but not considered a top priority.

However, it was recognized that if we can improve these systems, it would help achieve the UHC goals. Furthermore, the aspect of electronic information is relevant, as paediatricians providing quality information on disability also find websites and online patient support groups helpful.

**In summary, to increase global awareness, paediatricians doing nothing is not an option. A global paediatric network to support the sustainable development goals of the UHC seems the least paediatricians can do.**

December 2019 Bryony Coupe and Liesbeth Siderius

## Results UHC November 2019

### Q 1 Please indicate the country of practice

38 respondents in 24 different countries, per economy as defined by the World Bank:

#### High economy

Austria; Belgium; Croatia; Finland; Germany; Greece; Hungary; Ireland; Israel; Italy; Lithuania; Netherlands; Poland; Portugal; Slovenia; United Kingdom (16) n= 26

#### Upper Middle economy

Bulgari; Georgia; North-Macedonia ; Russia Federation; Sri Lanka; (5) n= 6

#### Lower-Middle economy

India; Moldova; Ukraine (3) n= 6

### Q2 Please indicate your medical specialty

36 respondents are paediatricians, one trainee in paediatrics and one medical geneticist

### Q3 I work in

16 in primary / secondary care; 18 in tertiary care; 2 are trainees and 2 have indicated another position.

Q4 Take measures to reduce maternal, neonatal, infant, and child mortality and morbidity and increase access to quality health-care services for newborns, infants and children (UHC nr 29)

What would be in your opinion necessary:

Improved efficiency of **preventive** child healthcare schemes n=26

Promotion of paediatric **primary care** n= 29

Improved integration of **digital health information** n=18

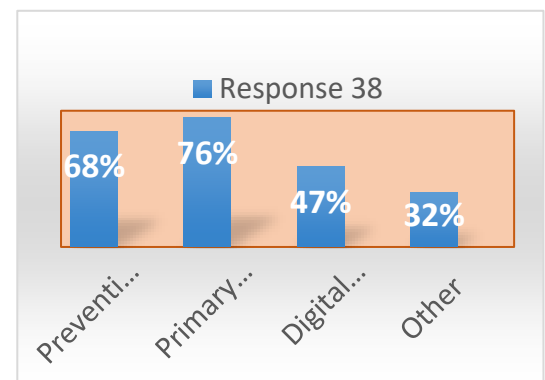
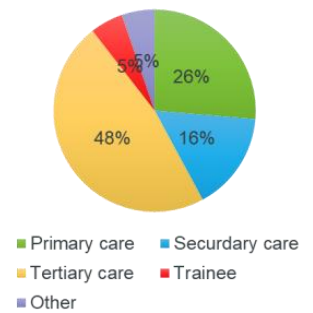
Other (please specify) n= 12:

- Education of families/parents on when to be concerned about their child. Quality easy access to primary care- More accountability from govt. and society-Child health should become EU political priority with EU Directive based regulation of child health care facilities and quality of service requirements-Changing the billing system in paediatrics and providing an adequate amount personnel on every single step of the healthcare system providing care to children-which is at the moment absolutely not the case-Better integration of systems

-paediatricians to gatekeeping positions : primary care !-All of the above- Easier (digital) availability of primary care paediatrician for minor issues, more budget for training/specialists to handle daily workload.- Coordination of care- Free or subsidised medical care to children- Shifting from hospital care to community- Implementations

Q5 Recognize that primary health care brings people into first contact with the health system and is the most inclusive, effective and efficient to enhance people's physical and mental health as well as social well-being (nr 13) Expand the delivery of and prioritize primary health care as a cornerstone of sustainable people-centred, community-based and integrated health systems, and the foundation of achieving universal health coverage, while strengthening of effective referral systems between primary and other levels of care... (nr 46)

Pediatricians working in:



What would to your opinion be necessary:

**Additional paediatric health and social care training for primary health care providers 84.21% n=32**

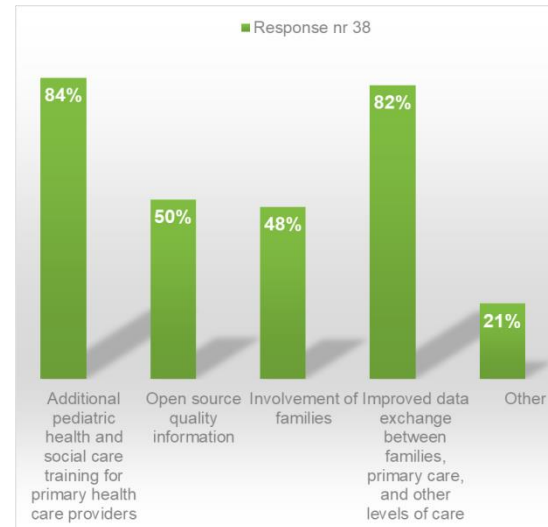
Open source quality information 50.00% n=19

Involvement of families 47.37% n= 18

**Improved data exchange between families, primary care, and other levels of care 81.58% n= 31**

Other n= 8 (please specify):

*-Stop active pushing of paediatrics from primary care and promoting GPs-Teach paediatric primary care to ALL medical students at the university-Nicely designed web-based information for young parents (I get asked about this by a lot of young parents and friends)-Not just open source and quality info, but equal access to these info , clear referral pathways- All of the above- In Austria, paediatric primary care needs to become more attractive. Financially and by quality of training.- Training and update knowledge and skills of grassroots level workers- Engagement of Family, Care Givers and Child*



Q6 Strengthen public health surveillance and data systems, improving routine immunization and vaccination capacities (nr31)At present do you use an electronic system for vaccination data:

No, we have paper registration 34.21% n=13

Yes, we have electronic registration 39.47% n=15

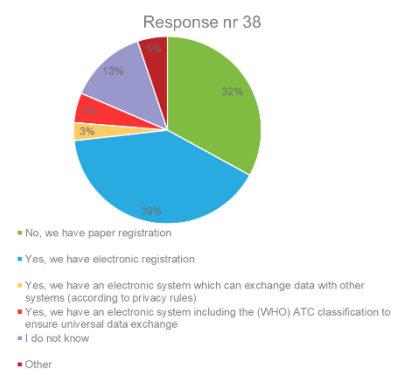
Yes, we have an electronic system which can exchange data with other systems (according to privacy rules)2.63% n=1

Yes, we have an electronic system including the (WHO) ATC classification to ensure universal data exchange 5.26% n=2

I do not know 13.16% n=5

Other (please specify) 5.26%= 2

*- There is currently no electronic registration of vaccinations. The Ministry of Health has set up an e-registration program. The system must be implemented within 1 year - But only for our region. Universal electronic database still pending.*



Q7 Strengthen efforts to address... rare diseases... as part of universal health coverage (nr34)What global action would be in your opinion necessary:

**Accessible diagnostics, regardless of the ability to pay 83.78% n =31**

Accessible treatment without exposure to financial hardship 78.38% n= 29

Wealthier economies to support middle and lower economies 56.76% n= 21

Other (please specify) 24.32% n=9

*-More deep networking and EU funded pan-European centres for single groups of RD - concentration of diagnostic and treatment facilities of tertiary care service for RD patients at least in EU (one centre per few countries?)*

*-Open source information to improve knowledge of medical care taker.*

*-Of course, it is best to be able to fully diagnose and treat all patients with rare diseases. Unfortunately, at least for some rare diseases, diagnosis and treatment are extremely expensive.*

*Producer companies explain the extremely high prices with high research and production costs for a small number of patients.*

*Perhaps the solution is to seek an effective unification for diagnosis*

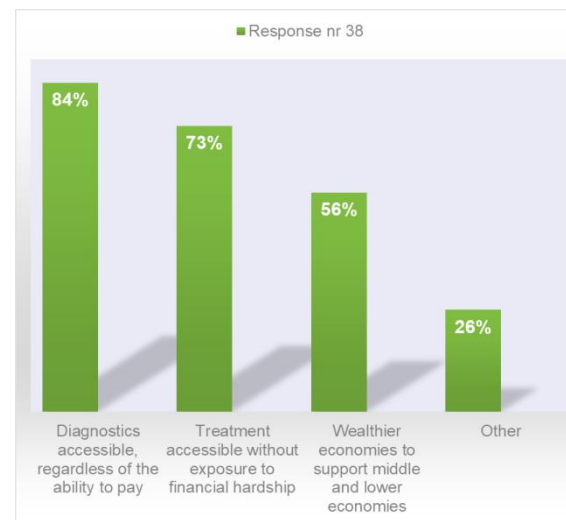
*and treatment at European level - this is likely to have enough patients and prices may fall. In short, a unified regional approach is required.-Disseminate knowledge-easy Dx via EHR, clear referrals-Digital information database/easier connection to specialists on rare diseases or suspected rare diseases*

*-Cheaper genetic diagnosis, some treatment such as for inherited rare diseases such as for Gauchers*

*or DMD (nonsense mutation) can be exorbitant.-More participation of governments- Equitable*

*distribution of resources across Health*

*Total Respondents: 37*



Q8 Increase access to health services to all persons with disabilities, remove physical, attitudinal, social, structural barriers, provide high-quality standards of care and scale-up efforts for their empowerment and inclusion (nr37) To your opinion:

**Paediatricians should take an active role in providing quality information on the cause of disabilities** 86% (n=30)

Disabilities may be caused by an undiagnosed rare condition 66% (n=23)

Disabled children have high quality care in my country/ state 43% (n=15)

Families with a disabled child become isolated from society 43% (n=15)

Families are empowered and do not need (paediatric) support 3% (n=1)

Other 16% (n=6)

*-Inequalities in paediatric service availability (no paediatricians in some regions)-I think the solution to the problem with these children is in an effective integrated medical and social approach. For me, this means: 1. Making an accurate diagnosis, which is the primary responsibility of paediatricians and general practitioners (depending on the organization of primary care in a country). 2. Very good collaboration between health and social services at primary care level. Affected children and their families should be given a clear short-term and long-term program in two directions - further diagnostic and therapeutic procedures needed, combined with community / local or national provision / opportunities to realize them.-patient / parent empowerment via real action PAGs- Disabilities may be educational such as autism and dyslexia that needs early detection and intervention. More facilities to educate doctors and public, more psychologists and other personal to be trained etc-ICF (WHO) usage to be made wide-spread (using Core Sets, at least)-Care and supports are often disjointed so better coordination of services is essential*

Q9 Improve availability, affordability and efficiency of health products by increasing transparency of prices of medicines, vaccines, medical devices, diagnostics, assistive products, cell- and gene-based therapies and other technologies across the value chain... (nr 50) In my country

Diagnostics are fully covered 50.00% n= 19

Treatments are fully covered 42.11% =16

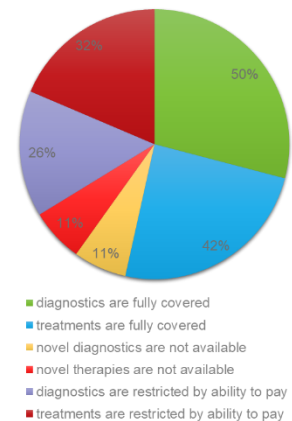
Novel diagnostics are not available 10.53% =4

Novel therapies are not available 10.53% n= 4

Diagnostics are restricted by ability to pay 26.32% n= 10

Treatments are restricted by ability to pay 31.58% n=12

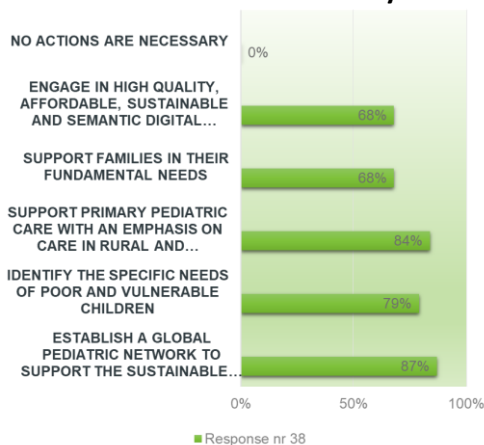
Total Respondents: 38



Q10 Increase global awareness, international solidarity, international collaboration and action towards the achievement of the universal health coverage by promoting national, regional, and global collaborative frameworks and fora (nr78)

To increase global awareness paediatricians could:

- **Establish a global paediatric network to support the sustainable development goals of the UHC 86.84% n=33**
- Support primary paediatric care with an emphasis on care in rural and distant areas 84.21% n=32
- Identify the specific needs of poor and vulnerable children 78.95% n=30
- Support families in their fundamental needs 68.42% n=26
- Engage in high quality, affordable, sustainable and semantic digital child health 68.42% n=26
- **No actions are necessary 0.00% n=0**



Other:

*-improve teaching about PPC to all medical students at the university- in order to create a global network, it may be advisable to first consider a regional network (such as a European network)- Increase social engagement- Care coordination- Identify corrupt process at international level especially by multi nationals- Learning from the past, the need for equitable care should not be used to deny quality care to those who can afford*

Source : <https://www.un.org/pga/73/wp-content/uploads/sites/53/2019/09/UHC-HLM-silence-procedure.pdf>