

Side event application / Formulaire de demande de réunion parallèle

Contact

Name/Nom: Dr. Canice Nolan, Permanent Mission of the EU	Date of application/Date de la demande: 29th March 2019
Delegation(s)/Délégation(s): Kuwait, Romania, EU Delegation	
Telephone, Email/Téléphone, courriel: canice.nolan@eeas.europa.eu +41 79 397 8879	

Description of proposed side event, including objective, expected results, proposed programme and speakers* / Description de la réunion parallèle proposée, y compris les objectifs, les résultats attendus, l'ordre du jour et les orateurs* :

An official side event to showcase rare diseases as a health field that can greatly benefit from the use digital technologies

The Side Event will serve to show the potential of digital health to achieve Universal Health Coverage. Rare diseases are at the forefront of these innovations and exemplify high added value of regional and global approaches. New digital tools are already being used to address the challenges of the 300 M people living with a rare disease to connect highly isolated patients, enable access and speed up diagnosis, refer to specialised medical expertise, to gather and share expertise on highly complex care, and accelerate clinical research over 6000 different diseases, each affecting a small population. Specific examples will be presented to explore their replicability and scalability at global level.

Objectives

Demonstrate the global added value of using digital technologies to improve access to diagnosis and care while reducing the cost of health services.

Inform the World Health Assembly discussions on how to integrate vulnerable population groups into UHC with a focus on digital health

Expected results

To leverage the experience in the field of rare diseases of the EU and other Member States like Sweden, Canada, Japan, Australia, UAE and Kuwait; update the audience on the potential of digital technologies to transform the delivery of health services and promote discussion on implementation from Member state perspectives within a UHC framework.

Proposed programme and Speakers

Opening remarks: Rare Diseases and Digital Health (EU, RO, KU, WHO – from UHC & Life Course or from Chief Scientific Office, tbc)

How digital technology can break isolation, connect and empower patients (Ågrenska Digital Academy; RareConnect & Care4Rare, Children's Hospital of Eastern Ontario)

How digital technology can accelerate time of access to diagnostic and help patients find the right experts or hospital and specialised services (EURORDIS – Rare Diseases Europe -Rare Diseases International)

How digital technology is transforming the organisation of health systems to network experts at regional and potentially global levels (the case study of European Reference Networks (ERNs) by a representative of the European Commission of from the EU Board of Member States on ERNs),

Panel discussion on replicability and scalability: Japan, Australia, UAE, Kuwait (tbc)

Background

The possibilities of Global Reference Networks, which had been imagined more than a decade ago, are finally within reach thanks to information technologies, their higher capacities and lower costs. Clearly digital technologies can improve the coordination of care and facilitate the collaboration of experts, but they can also be instrumental in the implementation of integrated care pathways, accelerating research, measuring quality and outcomes, delivering personalized care and enabling patient empowerment and engagement.

Drawing from the European example of European Reference Networks for 24 clusters of rare diseases, virtual networks of

clinicians will soon be in a position to adopt common standards with regards to data collection and interoperability. These networks are already relying on existing IT tools and platforms to deliver their mission. In the coming months and years, the ERNs will endeavour to develop a host of new services including virtual clinical consultations for rare disease patients across the EU; the identification of new emerging best practices and innovation in diagnosis and care; training and education of supra-specialisation and highly specialised surgery and intervention as well as the collection of shared common datasets and the creation of disease patient registries, that will drive forward the pace of research and development of treatments that offer the opportunities to care, and to cure which many patients and their families never hoped was ever possible.

Statement by Dr Tedros Adhanom Ghebreyesus, WHO Director-General

28 FEBRUARY 2018 | GENEVA - The vision of the Sustainable Development Goals is a world in which no one is left behind, including people who suffer from rare diseases. Just because a disease affects a small number of people does not make it irrelevant or less important than diseases that affect millions.

Rare diseases present fundamentally different challenges from those of more common diseases, especially for diagnosis. The small number of patients, the logistics involved in reaching widely dispersed patients, the lack of validated biomarkers and surrogate end- points, and the lack clinical expertise and expert centres all present significant barriers.

Medical expertise for each of these diseases is a scarce resource. Fragmented disease knowledge makes it critical that investments in research go hand-in-hand with investments in dedicated infrastructure and international networks such as biobanks, registries and networks of expertise. Where needed, these networks can also provide opportunities to train health professionals on rare diseases.

WHO's top priority is to support countries on the path towards universal health coverage, with the aim of ensuring that all people can access the health services they need, when and where they need them, without facing financial hardship. This includes access to diagnosis and treatment for people who suffer from rare diseases. Through the Fair Pricing Forum, WHO is seeking to foster dialogue between regulators, insurers, pharmaceutical companies and patient groups to ensure sustainable access to medicines, including orphan drugs. We welcome further discussions with the rare diseases community about how we can strengthen cooperation to ensure people with rare diseases can access the health services they need.

Event details / détails de la réunion

Date tbc

Time/Heure tbc

Expected number of participants/Nombre de participants attendus : 80-100

Exact title of the event/Titre exact de la réunion:

«How transformational digital technologies can contribute to leave no one behind in UHC: the case of rare diseases »

Interpretation/Interprétation

Interpretation may be provided in the official languages and the estimated costs are as follows: 2 languages: 2568 CHF; 3 languages: 5136 CHF; 6 languages: 11985 CHF.

L'interprétation peut être assurée dans les langues officielles aux coûts estimés suivants : 2 langues-2568 CHF; 3 langues : 5136 CHF; 6 langues : 11985 CHF.

Are interpretation services requested ? / L'interprétation est-elle requise ?

No/Non

(If yes, which languages)/(Si oui, en quelle langue)

English/Anglais

French/Français

Russian/Russe

Spanish/Espagnol

Chinese/Chinois

Arabic/Arabe

Other language/autre langue:

Invoice to be sent to/ Facture à envoyer à:

Name/Nom

Postal address/ Adresse postale

E-mail/Courriel

Room Layout/Aménagement des salles

Due to type of furniture and technical equipment in the room, the layout of the rooms cannot be changed. For information regarding the location and layout of rooms at the Palais des Nations, please see:

[http://www.unog.ch/80256EE60057CB67/\(httpPages\)/BAE3AF717207A5AF80256EF80049C552?OpenDocument](http://www.unog.ch/80256EE60057CB67/(httpPages)/BAE3AF717207A5AF80256EF80049C552?OpenDocument)

Le type de mobilier et les installations techniques dans les salles ne permettent pas de modifier l'aménagement de celles-ci.

Pour tout renseignement sur l'emplacement ou la disposition des salles au Palais des Nations voir le lien :

[http://www.unog.ch/80256EE60057CB67/\(httpPages\)/BAE3AF717207A5AF80256EF80049C552?OpenDocument](http://www.unog.ch/80256EE60057CB67/(httpPages)/BAE3AF717207A5AF80256EF80049C552?OpenDocument)

*Badges/ Badges d'accès

WHA side events are for participants of the WHA and, as such, panelists and participants should be drawn from those participating in the Health Assembly.

Les réunions parallèles sont réservées aux participants de l'Assemblée; Les orateurs de ces réunions doivent donc être choisis parmi ceux-ci.

Please complete the form and send it to / Merci de remplir le formulaire et de l'envoyer à

hggoverningbodies@who.int

by 29 March 2019