



EU4Health & 2022 Work Programme Stakeholders' Targeted Consultation

HEALTH SYSTEM –Break out session

Breakout session - Housekeeping Rules



- 'Unmute' yourself only when invited to speak
- Switch off your video
- Email SANTE-VISIO@ec.europa.eu for any technical issues



- **Indicate in full your organisation when joining Webex** (please reconnect in Webex and enter your details – organization, name)
- **Use the chat box** for any questions, remarks, or if you would like to speak **mentioning your organisation** clearly
- The **chat will be copied and workshop recorded** (if you do not wish to be recorded you can choose to listen and not intervene orally).

Breakout session – Health System

Moderator: Fabio D’Atri, Unit B5, Medicines: policy, authorisation and monitoring

Rapporteur: Giuseppina Luvarà, EU4Health Task Force



Purpose of the session:

Gather input from stakeholders on:

- Orientations, priorities and needs for the 2022 work programme
- Possible solutions that could fall under the objectives of EU4Health Programme with an EU added value

Structure of the session:

- Presentation of the most elaborated proposals
- Discussion
- Coffee break
- Open discussion and additional proposals

Breakout session - Health systems

Speakers:

- **Andrea Caffo**, Post Fata Resurgo-Vincere la SLA per ritornare a vivere
- **Yann Le Cam**, EURORDIS-Rare Disease Europe
- **Jaume Vidal**, Health Action International (HAI)
- **Maurizio De Plano**, Senior International Health Association (SIHA)
- **Ursula Trummer**, Center for health and migration
- **Maria Cristina Profili**, International Organisation for Migration (IOM)

EU4Health Work Programme 2022

Health Systems Breakout Session

"Amyotrophic Lateral Sclerosis CALL FOR ACTION"



**POST FATA
RESURGO**

Setting the scene

The **Amyotrophic Lateral Sclerosis (ALS)** - aka Motor Neurone Disease - is a relentlessly progressive neurodegenerative disease which attacks motor neurons in the brain and in the spinal cord resulting in the wasting away of muscle and loss of movement. Progress is generally rapid, with an average **life expectancy of between 2 and 5 years** from the onset of symptoms.

After 150+ years from first diagnosis, there is no cure for ALS yet.

ALS is 100% lethal: every 90 minutes someone is diagnosed with ALS and another one dies. This is simply unacceptable.

ALS Community is in **desperate need of help** and EC & EP have the duty and the power to **change the outcome of a story** that already seems to be written.

We are looking for a major quantum leap!

**time is a luxury no sufferer can afford,
especially an ALS sufferer.**



Drugs Early Access & Pathway Simplification

01	Allow (*) Use of Experimental Drugs	<ul style="list-style-type: none">• drugs w/ phase II completed & demonstrated safe and efficacy (even just in a subgroup of patients)
02	Compassionate Use Take-Over (*)	<ul style="list-style-type: none">• orphan drugs• drugs authorized for other purposes• drugs authorized outside the EU
03	Shorten Drugs Evaluation Time (EMA/EC)	<ul style="list-style-type: none">• dedicated team (**) for neurodegenerative drugs• max 45 days (EMA)• max 15 days (EC/DG-SANTE)
04	Streamline Drugs Approval Process	<ul style="list-style-type: none">• work with national authorities of Member States• eliminate redundant steps

(*) = in case there is no valid therapeutic alternative

(**) = as strengthening of “therapies for neurological and psychiatric disorders”
part within EMA

Centers of Excellence for NextGen Therapies

05

Centre of Excellence for
Regenerative Medicines

- clinical site for stem cells
- bioengineering
- organic tissue repair

06

Centre of Excellence for
Genetic Research

- clinical site for genome sequencing
- CRISPR-based methodology



The **European Commission** should be in charge of **Centers of Excellence** in order to establish both a Standardized & Common Framework and an Efficient & Effective end-2-end Workflow, maximizing the return on investments and the researchers' efforts and **reducing the waste of TIME, money as well as redundant studies.**

'27 countries working together'

[link](#)

European Health Union

Protecting the health of Europeans and collectively responding to cross-border health crises

The [pharmaceutical strategy](#) aims to [modernise the regulatory framework](#) and support research and technologies that reach patients. It rests on four pillars:



- Fulfilling [unmet medical needs](#)
- Supporting [a competitive and innovative](#) European pharmaceutical industry
- Enhancing resilience through diversified supply chains, environmental sustainability, and crisis preparedness
- Promoting high standards for medical products globally

"We cannot wait for the end of the pandemic to repair and prepare for the future. We will build the foundations of a stronger European Health Union in which 27 countries work together to detect, prepare and respond collectively."

Ursula von der Leyen, President of the European Commission, speaking at the World Health Summit (25 October 2020)

A photograph of seven wooden blocks arranged in a row on a light-colored wooden surface. The blocks are stacked to spell out the word 'CHANGE'. The 'C' and 'G' are on the top face of their respective blocks, while the 'H', 'A', 'N', and 'E' are on the front face. The 'G' block is tilted, showing its side face with the letter 'G'. The lighting creates soft shadows on the surface.

CHANGE

INACTION IS NOT AN OPTION

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POST FATA
RESURGO



#EU4HEALTH: HEALTH SYSTEMS BREAKOUT SESSION

Proposed Actions in the field of Rare Diseases

Yann Le Cam, Chief Executive Officer, EURORDIS

10 September 2021

EURORDIS.ORG



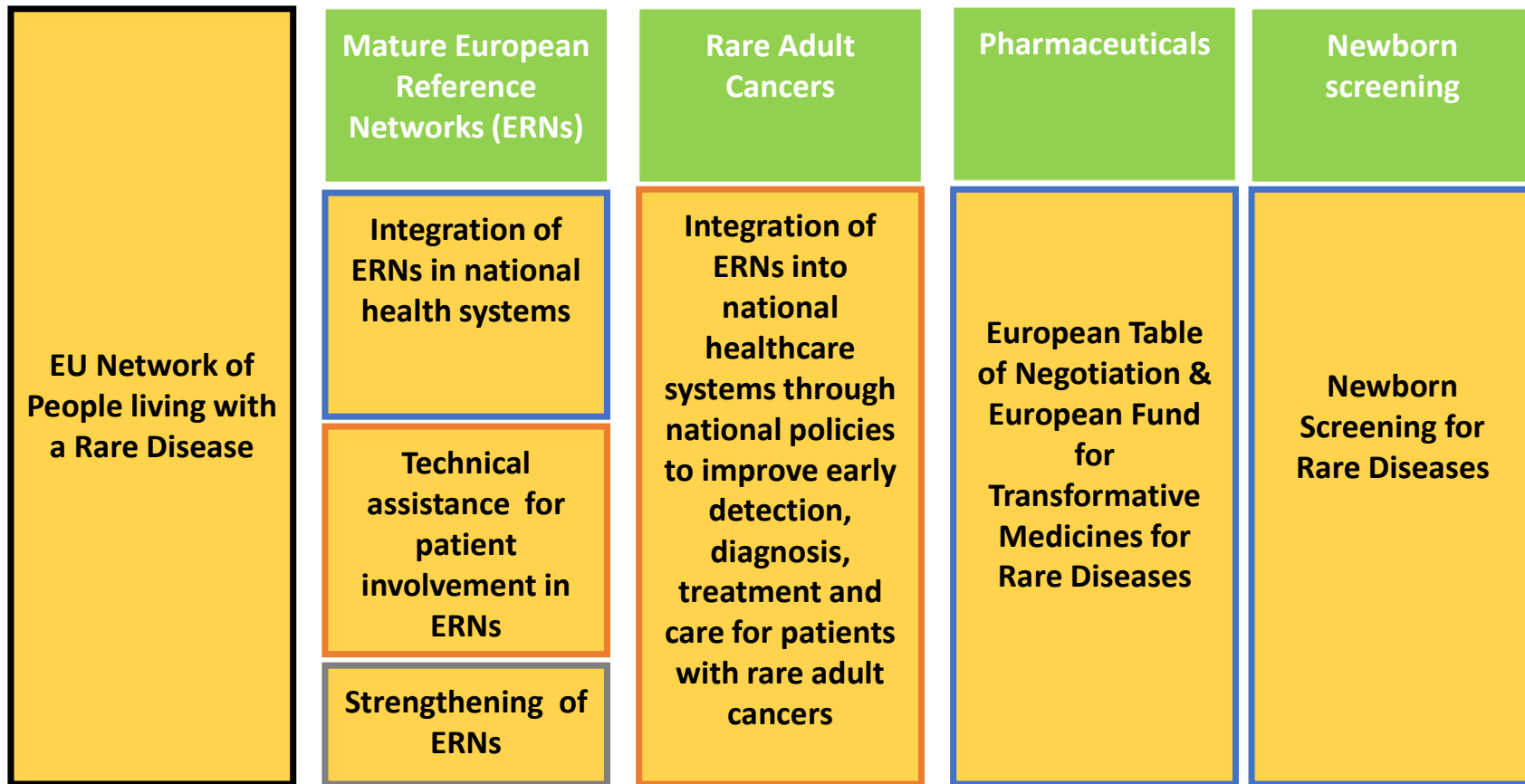
Rare diseases in Europe: 2030 goals



Proposals – strengthening health systems for the benefits of persons living with rare diseases

- Proposed actions in the field of rare diseases fully contribute to the Programme’s measurable objectives by:
 - complementing the strategies adopted and implemented by the EU Member States in rare disease policies, as well as in pharma/HTA/cross border healthcare/EHDS/cancer policies & legislation, by adding an authentic European perspective (rarity) and by integrating the national and EU level (networks)
 - improving accessibility, efficiency and resilience of health systems
 - strengthening European Reference Networks and their integration in national health systems
 - reducing inequalities in accessing healthcare
 - tackling non communicable diseases including rare cancers by improving diagnosis, prevention and care
 - supporting access to better healthcare for persons with rare diseases through cross-border health care
 - generating and disseminating health information and knowledge in an area where expertise is scarce

Proposals – achieving measurable results in EU4Health



Direct grants for Member States (Joint Action)

Direct grant on the basis of Article 195

Direct grant to bodies identified by the basic act

Public Procurement



Webinar EU4Health Work Programme 2022
Targeted stakeholders' consultation outcome
10 September 2021

Break-out Session: Health Systems

Jaume Vidal, Senior Policy Advisor, European Projects Team.



This presentation received funding under an operating grant from the European Union's Health Programme (2014-2020). The content of this report is the sole responsibility of Health Action International and represents its views only.



Foreword and introduction

- 40 years conducting **research** and **advocacy**
- Seeking to improve **access to safe, effective, affordable and quality-assured medicines/health technologies** and rational medicine use.
- For **everyone, everywhere**. Including within the **European Union**.
- Work with **European Commission, European Parliament** and **Member States**.
- Part of **Civil Society** coalitions and alliances both at the regional and global levels.

HAI and EU4Health Work Programme 2022

New framework and circumstances, same challenges and goals.

Need to compromise.

Main elements of intervention

Transparency
(Clinical trial data, prices, IP protection mechanisms)

Actionable Information
(evidence-based, unbiased, accessible)

Cooperation
(intra-institutional, across-country, stakeholders)

Sustainability
(Economic, political, scientific)

Citizen perspective - Wide scope - Pan-European approach

Way forward

- To counter information asymmetries and achieve more efficient and effective public interventions on access to medicines (and health technologies) :
 1. Make information available
 2. Enable accountability
 3. Ensure transparency
- To guarantee participation and buy-in from stakeholders and concerned parties
 1. Promote dialogue
 2. Build community

Thanks for your attention

Jaume@haiweb.org

www.haiweb.org



Maurizio Deplano
Strategy Lead
SIHA
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Disease prevention & health promotion

SIHA Proposal

A2T: Adherence to Therapy

September 2021

Needs and Challenges



Nearly 50% of patients do not follow the directions given by their GPs



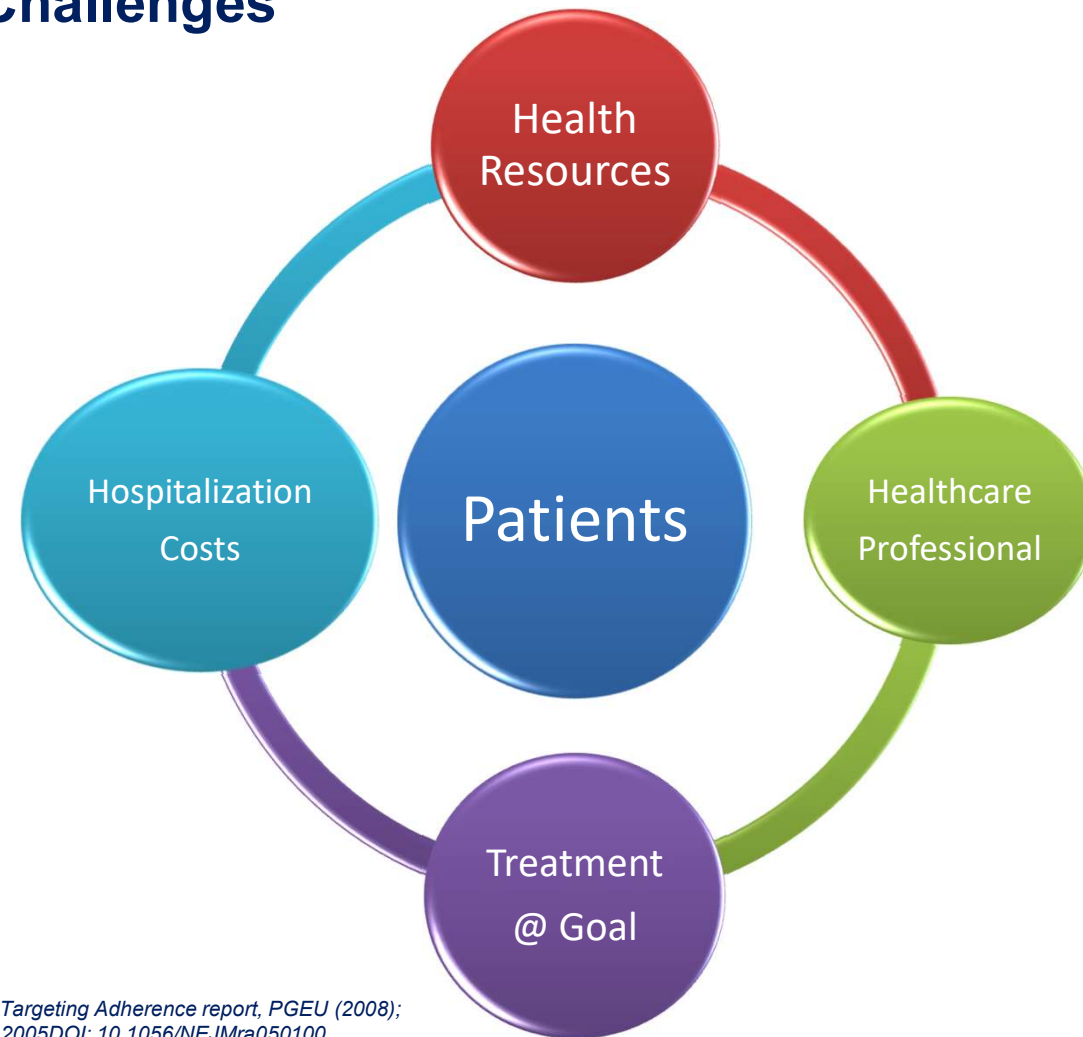
40% of over 65 use 5 to 9 drugs/week



About 200,000 of the premature deaths are due to wrong dosing or other types of non-adherence



1.25 €Bn every year: the estimated cost of non-adherence for the EU



Proposed Solution: Adherence to Therapy (A2T)

Objectives

- Involve EU Institutions in analysing the phenomenon, identifying causes and sizing socio-economic impact of poor A2T.
- Raising awareness among EU Population, focused on over-65s.

Outcomes

- Creation of a database on adherence by age, groups and diseases in the EU.
- Strengthen A2T data with digital tools and services(HealthWatch®).
- Development of training materials to implement Healthcare Professionals Train to Trainer (TTT) courses.
- Awareness leaflets for EU Population.
- Establishment of the European Day of Adherence to Therapy.

EU Value

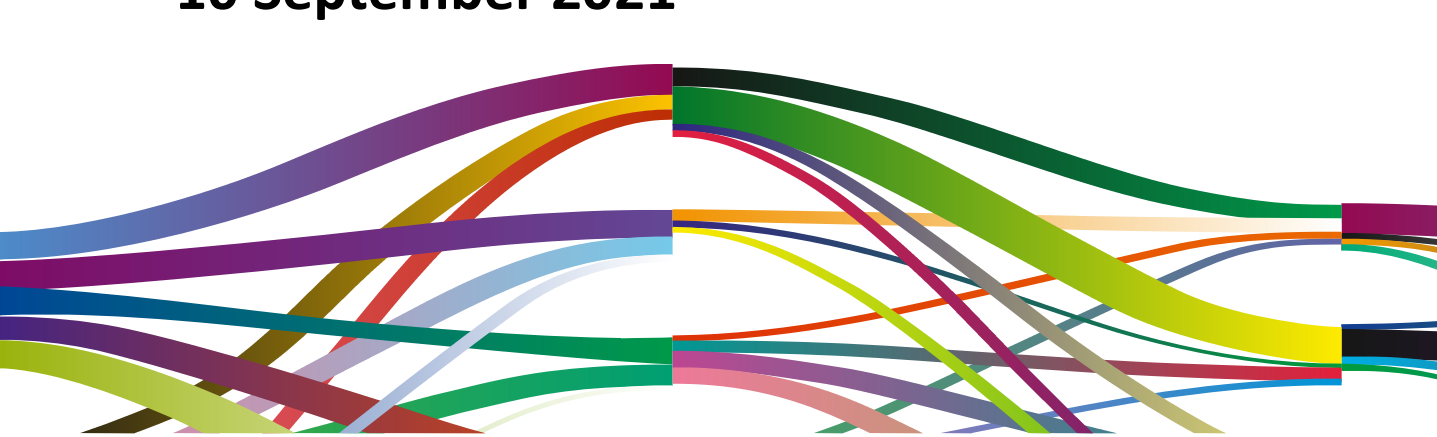
- Improvement of economic planning processes and A2T resources allocation to ensure health care sustainability.
- EU as a guide for the cultural change process needed to improve health status, especially in the elderly Population.



Thank you

24h care at home – challenges and solutions of non-institutionalised care models for Europe

Ursula Trummer
EU4Health Webinar
10 September 2021



24h Care at Home

Much needed care model in addition to institutionalised care
Culturally more appropriate in specific regions of EU
Reacting to changing patterns of intergenerational family solidarity

Rapidly growing market
Often informal labour
Low level of standardisation and quality assurance
Depending on temporary labour migration from poorer to richer countries

CENTER
HEALTH
MIGRATION

Trummer, Ursula (2020):
European Borders, COVID-19, and the Economy of Home Care
<https://globalejournal.org/global-e/august-2020/european-borders-covid-19-and-economy-home-care>

night train transports care workers between Timisoara, Romania, and Vienna, May 2020. (Photo credit: AFP)

Some factors home care is built on : The case Austria and Romania

- Cash benefit scheme covering people with disabilities/in need of care to support care provision at home – 460,000 persons registered as in need of care
- Legalisation of a grey 24-hour home care sector by gradual and complex legislative changes in 2006, 2007, and 2008
- In 2020, Romania is the leading source country of 24-hour care providers in Austria (app. 40,000 of 60,000 caregivers working on self-employment contracts) mostly brokered by agencies
- Usually working on four-week alternating shifts
- During COVID-19 lock-down and closure of borders, dependency of home care sector on migrant carers became apparent

Important for good health care provision at home:

- Incentives to choose (legal) home care models
- Ensure good training (health related/culture-related) of carers
- Ensure appropriate working conditions for carers
- Management of temporary migration

Solutions

- ❑ Integration of 24h care into legal structures of health care provision in Europe
- ❑ Quality standards for 24h care: Quality of care in a specific worksetting and relationship
- ❑ Quality standards for agencies
- ❑ Development of models of circular migration of 24h carers from third countries

Romanian care workers accompanied by police and security at Vienna's airport in May, 2020. (Photo credit:

Population pyramids 2020

Austria ▼
2020

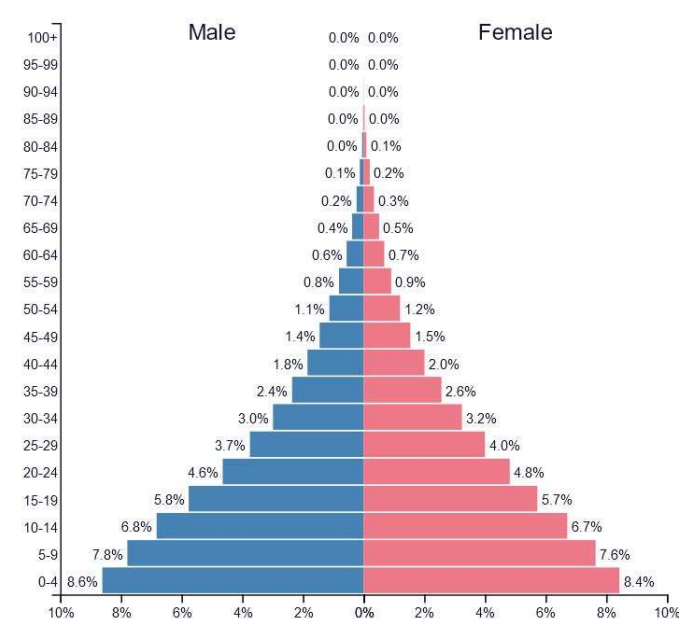
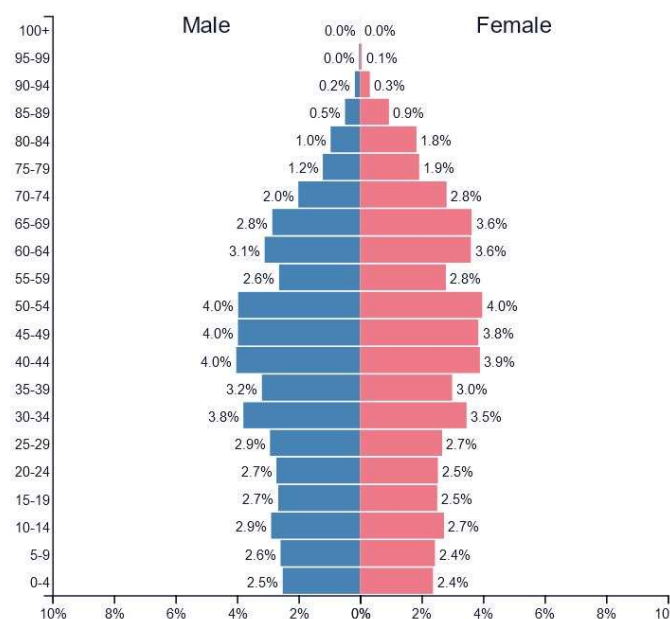
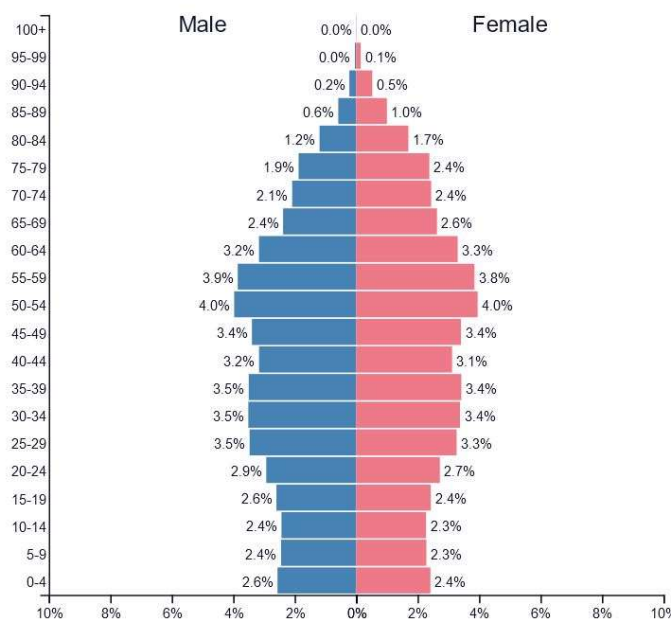
Population: 9,006,400 2020

Romania ▼
2020

Population: 19,237,681 2020

Uganda ▼
2020

Population: 45,741,000



IOM contribution EU4Health WP 2022: targeted stakeholder consultation outcome -Health Systems-

Speaker: Dr Maria Cristina Profili, Senior Migration Health Regional Advisor

IOM Regional Office EU/EEA-Migration Health Division

Brussels, September 10, 2021





Ensure the orderly and humane management of migration to promote international cooperation on migration issues

Defining “migrants” as **vulnerable population**:

- An umbrella term
- Not defined under international law,
- Person who moves away from his/her place of usual residence
- Within or across an international border
- Temporarily or permanently
- For a variety of reasons
- Regularly or irregularly
- By choice or by force





Framework



2030 Agenda for Sustainable Development key principle is to “leave no one behind”

3 GOOD HEALTH AND WELL-BEING



SDG 3.8 - Achieve Universal Health Coverage, including financial risk protection, access to quality essential health care services and access to safe, effective, quality and affordable essential medicines and vaccines for all

10 REDUCED INEQUALITIES



SDG 10.7 - to facilitate orderly, safe, and responsible migration and mobility of people, including through implementation of planned and well-managed migration policies

17 PARTNERSHIPS FOR THE GOALS



SDG 17.18 - to increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, **migratory status**, disability, geographic location and other characteristics relevant in national contexts

Migration Health Needs



272 million international migrants (UNDESA, 2019)

Migrants and mobile populations face many obstacles in accessing essential **health care** services:

- Lack of migrant-inclusive health systems and policies
- Language barriers
- Migration status e.g. irregular

Mobility impacts individual's physical, mental and social well-being vulnerability

Which are the important objectives to be addressed by EU4Health funding?

IOM focus on **vulnerable groups among which migrants**:

- Disease prevention and health promotion (*specific objective 1*)
- Strengthen health data, digital tools & services, digital transformation of healthcare (*specific objective 6*)
- **Enhance access to healthcare (*Specific objective 7*)**
- Development & implementation of EU health legislation & supporting evidence-based decision making (*Specific objective 8*)
- International health initiatives & cooperation (*Specific objective 10*)

Enhance access to healthcare (Specific objective 7)

Strengthen Primary Health Care and reinforcing the integration of care, within the principle of Universal Health Coverage and equal access to quality healthcare:

Objectives:

- Support migrant-inclusive health systems and **policies** and **plans** at national and European level which deliver, facilitate and promote equitable **access**.
- **Knowledge transfer** actions and Union level cooperation to assist **national reform processes** towards improved effectiveness, accessibility, sustainability and resilience **health systems**;
- Support the **digital** transformation of healthcare and **health information systems**, through benchmarking and capacity building as well as supporting the **digital upskilling of healthcare professionals**;
- Migrants' **health workforce** integration and capacity building, to continue being a central enabler of sustainable development of economies and societies;
- IOM strengthens intercountry coordination and **partnerships** to enhances technical and operational capacity in the Member States.

Description of solutions proposed including (1) objectives, (2) outcomes, and (3) EU added value

Expected outcomes:

- Health systems across the EU implement standardized practices on migrant health, elaborated in cooperation with the EU;
- Migration health becomes part of the national health plan and national budgets;
- Workforces dealing with migrants are equipped to collaborate and face new challenges.

EU added value:

- EU a key stakeholder in supporting IOM policies;
- EU has an active role in fostering international partnerships e.g. United Nations Network on Migration.

Thank you for your attention

IOM MHD RO BRUSSELS:

brusselsmigrationhealthunit@iom.int

Breakout session – Health System

Moderator: Fabio D’Atri, Unit B5, Medicines: policy, authorisation and monitoring

Rapporteur: Giuseppina Luvarà, EU4Health Task Force



**Discussion on the topics
introduced by the Speakers**

Coffee break

...we will start at 12:20

Breakout session – Health System

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Open discussion and additional proposals

***Short and target intervention on the needs/challenges
and solutions to be addressed in the EU4Health work
programme 2022***

***Please address your intervention through the chat or
raise your hands – Unmute when you are invited to speak***

Please return to the plenary session

...we will start at 13:00