

# EU4Health Programme

2023 Stakeholders' event

*08 July 2022* 

# 2023 Stakeholders' Targeted Consultation on EU4Health priorities, strategic orientations and needs

Question 10. From your knowledge and experience can you indicate any action that could be considered as a success story for the achievement of the specific objectives of the Programme and that would provide an EU added value?



# Strand of action 01: Crisis preparedness

- Blood transfusion in emergency situations
- Prevent the preventable



# Strand of action 01: Crisis preparedness

Blood transfusion in emergency situations



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#### **IDEAS**

- Develop a crisis preparedness concept including training programs for <u>blood transfusion in emergency situations</u> which includes coordination between key stakeholders and interregional/intercountry collaboration.
- Emergency situations may include mass casualties and patients with life-threatening bleeding when resources are scarce. It also includes blood shortages due to reduced access to blood donors (as in pandemics) or due to limited access to necessary equipment needed for collection and transfusion of blood.
- The concept will strengthen cross border health care systems and capacities by co-ordination and collaboration. This is of major importance in scarcely populated areas like in the Arctic region, but also for emergency health care services in general.
- The concept will target high as well as low probability crisis situations with a high impact on emergency health care systems.

How this will help to strengthen the EU Health policy and enhance the health of European citizens?

#### CHALLENGES

- The current European security policy situation with a constantly changing risk picture calls for cross border blood preparedness approach.
- The need to develop emergency blood transfusion capacities with high credibility and trust.
- Need for systems for interregional/intercountry coordinated training of health personnel in emergency blood transfusion.
- Lack of redundant systems for re-supply of blood and equipment needed for collection and transfusion of blood.
- Ensure human resources for contingency training of health personnel and establishment of emergency donor panels in remote areas.

Which contribution to the achievements EU4Health objectives?

#### LESSONS LEARNT

- Establish a program for emergency blood collection and transfusion for treatment of patients with life-threatening bleedings
- Develop training programs for all stakeholders that include practical and digital learning tools and "train the trainers" courses for the maintance of the program.
- Allocate sufficient resources to oversee the implementation and continuation of national and cross border systems for the use of emergency blood collection
- Further develop and build competence networks across regions and borders
- Implement digital solutions for management of emergency donor panels

# Strand of action 01: Crisis Preparedness

### Prevent the preventable



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#### BACKGROUND

Vaccines are one of the greatest public health preventative tools, saving millions of lives every year<sup>1</sup> and contributing to the sustainability of healthcare systems<sup>2</sup>. The COVID-19 vaccines alone, in its first year of implementation, saved nearly 20 million lives globally3.

Despite those figures and evidence, vaccination and immunisation programmes do not have their prominent place in the broader arsenal of prevention policies and budgets. To sustain overall health gains and maintain high vaccination coverage rates, vaccination programmes in the EU need significant increased support and recognition of their value.

In the EU, a routine immunisation across the life course could protect against 20 life-threatening infectious diseases, yet there is significant discrepancy in the vaccination offer to citizen across the EU, ranging from <u>8</u> to 17 publicly funded vaccines depending on the country<sup>4</sup>. Almost 80% of European governments spend less than 0.5% of their healthcare budget on immunisation programmes<sup>5</sup>.

As laid out by a recent study<sup>6</sup>, there is a significant gap in equity of access to innovative vaccines in the EU, varying from 2 to 10 years depending on the country.

The COVID-19 pandemic clearly demonstrated the <u>added value</u> of European cooperation to strengthen and maximise the efforts in the fight against infectious diseases.

### How will this help to strengthen the EU Health policy and enhance the health of European citizens?

Based on the recommendations of EU-JAV<sup>7</sup>, and taking inspiration from the success story of the European Beating Cancer Plan<sup>8</sup>, the EU4Health Work Programme could support the development of a real moon-shot mission on infectious diseases, with an important role given to innovation with one-health approach – looking holistically at threats from infectious diseases, vaccination programmes' performance and information to citizens.

The EU could take the lead and campaign for becoming the best-immunised region in the world and contribute significantly to the post-COVID recovery. By protecting their population against infectious diseases, the EU Member States can foster a stronger and more resilient safeguard against known and unknown threats, including against AMR and climate change-related developments, increasing the resistance and readiness of their health systems in case of future pandemics.

Lesson learnt from COVID-19 pandemic is that there is still a lot to be done to achieve sustainable and equitable access to vaccination in Europe. Looking at the differences in the COVID-19 vaccination uptake between Eastern and Western Europe, the disruption of routine vaccination programmes, the rise of vaccine hesitancy – to mention a few. Yet, the EU Joint Action on Vaccination (EU-JAV)<sup>9</sup> finalised its work in March 2022. The European Commission Roadmap<sup>10</sup> on cooperation against vaccine-preventable diseases is coming to a close in December 2022.

The moon-shot mission should call for a renewed commitment on tackling infectious diseases, in normal time as well as crisis. Based on a clear and broad vision, it should follow up on actions from the EU-JAV and Roadmap and close the gaps in the current EU activities. A central role should be given to addressing cross-border health threats, such as AMR and climate change, detection of new threats, and implementation of routine vaccination programmes at all stages of life.

To undertake the necessary paradigm shift, the EU4Health should bring forward programmes to help Member States reallocate their public funding and investment in prevention, including vaccination reaching a more durable and balanced approach in comparison with the budget devoted to treatments.

The EU can play a crucial role in providing guidance for the set-up, implementation and performance check-up of immunisation programmes e.g. by promoting and sharing best practices on: sustainable immunisation financing; transparency, consistency, inclusiveness and timeliness and vaccine access pathways and decision-making processes; life-course vaccination, conducting information campaigns amongst citizens.

# Strand of action 01: Crisis Preparedness

### Prevent the preventable (continued)

#### Which contribution to the achievements EU4Health objectives?

A moon-shot mission against infectious diseases could become a success story for severalobjectives of EU4Health Programme, focusing on prevention, preparedness & response to cross-border health threats. Ensuring that all Europeans are protected against infectious diseases will contribute to a vision for a healthier EU and to our collective response to cross-border health threats.

#### Conclusion

If the EU4Health <u>Programme</u> is the European Union's response to the current public health emergency and paves the way towards a European Health <u>Union</u>; it is expected to make a significant contribution to the post-COVID-19 recovery and aims to bring a contribution to the long-term healthcare challenges by building stronger, more resilient and more accessible healthcare systems.

The EU4Health Work <u>Programme</u> could support the development of a real moon-shot mission on infectious diseases that could be the necessary paradigm shift for anticipation and durable financing against threats from infectious diseases.



- Atrial fibrillation screening & therapies
- Harm reduction networking & experts' collaboration
- Harmonized data on NCDs
- Mental health
- Mental health repository for evidence
- New-born screening
- Out-of-hospital cardiac arrest
- Venous thromboembolism
- Centralized remote monitoring service for patient at high risk of sudden cardiac death
- Screening programmes and early detection of Structural Heart Diseases
- Raising awareness on healthy lifestyle and prevention
- Joint screening on chronic kidney disease, heart disease, diabetes and hypertension
- Mental health & well-being
- Centralized remote monitoring service for patient at high risk of sudden cardiac death
- One health approach: bridging gaps across sectors to preserve and improve the health of humans, animals and the environment
- One Health approach
- Cross-sectorial action against mental health and neurological disorders
- Serious game applications



Atrial fibrillation screening & therapies



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#### BACKGROUND

Atrial fibrillation (AF) is the most common sustained cardiac arrhythmia, occurring in 1–2% of the general population. Over 6 million Europeans suffer from this arrhythmia, and its prevalence is estimated to at least double in the next 50 years as the population ages. AF confers a 5-fold risk of stroke, and at least one in four of all strokes is attributed to this arrhythmia. Ischaemic strokes in association with AF are often fatal, and those patients who survive are left more disabled by their stroke and more likely to suffer a recurrence than patients with other causes of stroke. In addition, AF triples the risk of heart failure, which is one of the cardiovascular epidemies of the XXI century.

#### **IDEAS**

- Better understanding of the value of AF screening (wearables) and its impact on stroke (trials and registries)
- Support successful AF therapies, such as catheter ablation, by promoting education, facilitate training and implementation of them.

### How this will help to strengthen the EU Health policy and enhance the health of European citizens?

The growing epidemy of AF with increasing numbers due to aging population, better awareness and early detection will create a higher demand of AF catheter ablation. Continuous knowledge and technical improvements of this latter will further increase the demand of it.

#### CHALLENGES

- Need to collaborate with companies in the development of screening tools
- The demand for more AF ablation operators will not be covered by the current number of professionals in training

#### LESSONS LEARNT

 Need for a stronger collaboration between EU, local governmentes and Scientific Societies Which contribution to the achievements EU4Health objectives?



### Harm reduction - networking & experts' collaboration



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"....there is a need to protect people in vulnerable situations, including those suffering from mental illness and those living with or most affected by communicable or non-communicable diseases and chronic diseases, and to promote activities, which address and prevent the collateral impact of health crises on people belonging to such vulnerable groups and actions that improve mental health."2

"The objective is to ensure the participation of health NGOs in activities that are necessary to implement one or more specific objectives of the EU4Health Programme. Hence, operating grants should provide support to the functioning of certain NGOs during 2022 for activities, including awareness-raising on various health aspects, communication and dissemination, capacity building and training, expert collaboration and networking."

#### BACKGROUND

Drug use remains a topic of growing concern in Europe. Every year, Europe faces a more complex drug situation, characterised by high availability and greater diversity in consumption patterns. This complexity is reflected in an increasing recognition that drug use is linked with, or complicates, how we respond to a wide range of today's most pressing health and social issues.

Around 83 million or 29 % of adults (aged 15-64) in the European Union are estimated to have used illicit drugs at least once in their lifetime. In 2019, around 1 million were estimated high-risk opioid users, of which 510 000 were engaged in opioid substitution treatment. Opioid users accounted for 28 % of drug treatment requests, while 74% of fatal overdoses involved opioids, often combined with other substances (EMCDDA Drug Report, 2022). 1

Harm Reduction (HR) interventions are practical, feasible, (cost) effective and evidence-based, in particular regarding HIV/AIDS and HCV prevention, treatment and care among People Who Use Drugs (PWUD). C-EHRN is a European civil society network with more than 270 members in Europe that supports policy and practice of harm reduction in Europe, thereby contributing to public health in general and the health of PWUD in particular. The overall objective of C-EHRN is to improve access to and the quality of harm reduction and other low-threshold services for PWUD - including other related vulnerable and marginalised people - and to enhance policy and practice while increasing social inclusion.

From 2018-2021, C-EHRN received a four-year Operational Grant which catalysed the development and implementation of activities in the field of networking, monitoring and data collection, capacity building and advocacy. This Operating Grant is continued in 2022.

IDEAS

Foster networking and expert collaboration with the network members, partners, other networks and European agencies, including the EMCDDA and the ECDC.

Improve and maintain a European community-based monitoring and data collection framework in the field of drug use and harm reduction, including communicable diseases such as HCV.

Improve and scale-up capacity building and knowledge exchange of community-based and community-led health and harm reduction services

Improve dissemination, awareness raising and advocacy to promote good practices and evidencebased interventions in the field of harm reduction HOW THIS WILL HELP TO STRENGTHEN THE EU HEALTH POLICY AND ENHANCE THE HEALTH OF EUROPEAN CITIZENS?

C-EHRN's networking and expert collaboration increase impact, sustainability and synergy of activities by representing the needs and interests of its members, partners and target groups and bringing their knowledge and expertise to a European level.

It increases the availability and quality of existing health data. C-EHRN Civil Society Monitoring complements and cooperates with other monitoring systems, such as ECDC and the EMCDDA.

It improves existing knowledge and understanding of emerging local drug trends and potentially related risk behaviours, for example regarding the transmission of blood-borne infections.

C-EHRN capacity building activities supports and strengthens the role of community-based and community-led health and harm reduction services. More knowledge and capacities will improve quality in (drug-related) health policy, practice and care.

C-EHRN coordinated and targeted dissemination, awareness raising and advocacy contributes to the development of evidence and practice-based health and drug policies and, therefore, to better health outcomes.

### Harm reduction – networking & experts' collaboration (continued)

#### CHALLENGES

Need for an integrated and balanced drug policy approach in Europe.

Need for targeted disease prevention, social determinants of health outcomes and health promotion regarding illicit drug use.

Need to improve access, quality and coverage of community and evidence-based health and harm reduction services in EU Member States and neighbouring countries.

Need to address health and social inequalities among PWUDs and other marginalized communities, linked to stigma and criminalisation.

Need to address overdose mortality, by implementing effective harm reduction interventions.

Need to bridge the gap between policy making, research and practice.

High prevalence of HCV among PWUD and current gaps in data regarding prevalence, prevention, diagnoses, treatment and linkage to care.

#### WHICH CONTRIBUTION TO THE ACHIEVEMENTS EU4HEALTH OBJECTIVES?

C-EHRN activities focus on prevention, health promotion and health determinants regarding illicit drug use. The Network addresses in an integrated manner the different social and health challenges and needs in the field in all areas of work. This includes networking and collaboration with relevant stakeholders, the collection of data and information through a European civil society monitoring and research framework, the organisation of capacity building events and knowledge exchange and dissemination, awareness rising and advocacy activities.

C-EHRN addresses the different needs by involving the knowledge and expertise of its members – including, among others, community-based services, communities themselves, researchers, law enforcement or policy makers - and by organising expert consultations. This increases the impact of activities, contributes to the implementation of good practices in the field of HR, and contributes to and improvement of health outcomes in marginalized and underserved individuals and communities in Europe.

#### LESSONS LEARNED

Civil society organisation and networks are key in the development and implementations of evidence and human-rights based health and drug policies.

PWUDs and other marginalised populations have specific needs and specific (EU) funding is required to address these needs and improve access, quality and coverage of services.

Community-based services targeting PWUD need to be integrated in the continuum of health care.

Community-based research and monitoring needs to be strengthened and supported.

Need to adjust to technical developments and transformations, including digitalization.

#### WHAT CAN WE DO BETTER FOR GREATER IMPACT?

Increase opportunities for civil society organisations to organise and participate in action Grants. Maintain opportunities for Operational Grant Funding in the future EU4Health work plans to ensure the independence, sustainability and health impact of European civil society networks.

Improve the meaningful participation of civil society in the development of health programmes and work plans. This includes the reinforcement of current existing Civil Society fora.

Address the specific health challenges and needs of PWUDs and other marginalised groups in the EU4Health Programme and work plans (including HIV/AIDS and HCV prevention, treatment and care, community-based health and harm reduction services).

More integrated approaches and cross-cutting initiatives between different EU Funding Programmes to increase synergy and impact.



### Harmonized data on NCDs



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#### BACKGROUND

Currently, there is no harmonised, centralised mechanism for the collection, monitoring, and analysis o data on NCDs across the EU. Yet, such data is critical to improving NCD prevention and management plan in Europe and ensuring cost-efficient health systems' responses to chronic diseases. With a major focu on disease prevention, the EU4Health programme 2023 can help address those gaps, to set up harmonised EU NCDs registry for integration into the European Health Data Space. This would provid comparable and robust evidence, integrating data collected through various systems in Europe and usin common indicators.

Further, the COVID-19 pandemic had a significant impact on people living with chronic diseases and thos without any pre-existing conditions. It has further underscored the clinical links between communicable an non-communicable diseases – yet major gaps in data collection between these areas; and the important role of the EU in supporting data collection. Future actions to support crisis preparedness should take holistic approach to health challenges, and support integrated surveillance and response mechanisms.

#### IDEAS

- Goal: Build a uniform EU NCD registry fully operational by 2030 integrated under the European Health Data Space (EHDS)
- Action: An EU funded project/action to develop a pilot model of a centralised mechanism for the collection, monitoring and analysis of data on NCDs at EU level (bringing together existing registries, data collection efforts and ongoing projects). The project shall also map existing data collection tools, information gaps, agree indicators/data sets to develop interoperable registries across Europe by 2030, identify role of stakeholders - including ECDC's greater role in collecting data on the links between infectious diseases and NCDs.
- Future registry to include health economic data on NCDs.
- Impact: An integrated registry would be a major achievement for Europe, reflect further the EU added value of action in the field of health and the benefits of pooling together expertise and resources at European level.

Strengthening EU policy & citizens' health: An integrated registry would provide robust, comparable evidence to evaluate the effectiveness of strategies, policies and actions to address NCDs, inform decisions at all levels and adapt existing/new disease management guidelines. Further, it would show the cost-effectiveness of prevention and help stimulate investment in the area.

Harmonized data on NCDs (continued)

#### CHALLENGES

- Currently, there is no harmonised approach for the collection, monitoring and analysis of NCDs data in the EU
- Information gaps remain on NCDs
- Additional efforts are needed to collect robust health economic data
- Relevant bodies/stakeholders may collect important data yet it lacks synergy/complementarity.
- Only 3% of health budgets are allocated to prevention on average across Europe – while the prevalence of NCDs continue to grow and there is plenty of robust evidence on cost effective prevention measures.

**Contribution to the achievement of EU4Health objectives**: This project would help improve the efficacy and impact of NCD prevention and control measures in Europe, develop better and more targeted screening programmes, fight health inequalities.

#### LESSONS LEARNT

- There is a clear need to integrate surveillance mechanisms across disease areas - such as communicable and non-communicable diseases.
- COVID-19 set precedent of achievable collaboration when it comes do data collection, it now needs to be transposed to the area of chronic disease.



### Mental health



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Psychedelic Access and Research European Alliance - PAREA

10. From your knowledge and experience can you indicate any action that could be considered as a success story for the achievement of the specific objectives of the Programme and that would provide an EU added value? EU Mental Health Strategy

#### BACKGROUND

Mental health is critically important to everyone, everywhere. It touches every part of our lives. We are not either mentally healthy or mentally ill. Mental health exists on a complex continuum, with experiences ranging from an optimal state of well-being to states of great suffering and emotional pain. So mental health is not defined by the presence or absence of mental disorder and, as such, it is everyone's business. Core business.

And yet, we continue to fail too many individuals, families and communities affected by mental health conditions. We fail to create societies where our wellbeing is priority and where economy is designed to support us to thrive as individuals and communities.

We must address the mental health crisis as thoughtfully as we can, with all the options on the table. Representing a new alliance: Psychedelic Access and Research European Alliance (PAREA), I'd like to point out to one particular example: research into psychedelic-assisted therapies (PAT). A growing, rigorous, and compelling body of research strongly suggests that PAT – a unique combination of a drug and therapy – may be a potent new class of treatments for mental health conditions and other brain disorders, including addictions. When approved, those treatments will need to have a significant medical and therapeutic oversight built into them and their effectiveness will be also contingent upon how strong and well-resourced our general mental health care is, with qualified mental health care workforce, including therapist, as well as how much we will prioritize aftercare provisions and community-based care.

How this will help to strengthen the EU Health policy and enhance the health of European citizens?

#### IDEAS

- Acknowledge that mental health and wellbeing is a societal top priority
- · Bring all countries and stakeholders together to address it
- Devise comprehensive, holistic and multisectoral EU mental health and wellbeing plan
- Allocate considerable time and resources for its implementation
- Integrate mental health at all levels of general heath
- · Promote community based mental health services and support
- Develop modes of broad, long-term and multidisciplinary care involving integrated teams of psychiatrists, psychologists, primary-care nurses and social workers. Just getting a person through a mental-health crisis often doesn't help their long-term prospects. They need support to stay on their medication, to look after their general health and to get their personal lives back on track.
- Incentivise innovation and promote cutting edge science such as psychedelic-assisted therapies



### Mental health (continued)

Which contribution to the achievements EU4Health objectives?

#### CHALLENGES

- A chronic shortage of mental health resources that continues to this day. WHO's most recent Mental Health Atlas showed that in 2020, governments worldwide spent on average just over 2% of their health budgets on mental health
- A <u>WHO scientific brief</u> indicated that rates of already-common conditions like depression and anxiety went up by more than 25% in the first year of the pandemic, adding to the nearly one billion people who were already living with a mental disorder.
- One in six Europeans is diagnosed with a mental illness in any given year and 56% of patients with major depression receive no treatment at all
- Omnipresent stigma
- Mental health conditions are not considered deadly and yet this couldn't be further from reality:
  - Nearly 130 000 people die by suicide every year in WHO European Region
  - People with severe mental health conditions die 10 to 20 years earlier than average. Most of these deaths
    are due to preventable diseases, especially CVD, respiratory disease and infection, which are more common
    in people with mental health conditions. In these cases, having a mental health condition may not be the
    cause of death, but it is likely to be a major contributing factor
- Mental health care evolved to deal with mental-health crises, not provide longer-term management and recovery
- The majority of people with mental disorders live in socioeconomically deprived, lower income settings. This
  perpetuates a vicious cycle between mental health and poverty
- There is very slow progress in developing new treatments. E.g., only seven neuropsychiatric drugs have been approved since 2015, while the field of oncology has seen approvals of 80 drugs.
- Promising novel areas of treatments continue to emerge such as psychedelic-assisted therapies. However, these
  still carry a heavy stigma of party drugs and research into them is hampered due to them being in the most
  restrictive category in the UN drug convention stating they have no medical potential.

How can we do better for a greater impact?

#### LESSONS LEARNT

- · Mental health and wellbeing concerns all of us
- Inaction is no longer an option its costs are too high to all of us
- An example of EU Cancer plan shows us that, when there is political will and commitment, a lot can be done together.
- New promising innovations emerge, such as psychedelic novel treatments, and we need to incentive them.



Mental health repository for evidence



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#### BACKGROUND

Mental health is one of the major challenges of every health system in the world. Due to lack of funding most mental health systems within the EU need reinforcement to meet with the increased mental health needs. The WHO proposed a model to organise mental health services in a more efficient way (WHO, 2009). Most countries still struggle today to achieve this organisational model.

#### IDEAS

- EFPA, the European Federation of Psychologists' Associations, proposes to create a repository for evidence – based mental health interventions for each of the different layers of the WHO pyramid.
- The repository is available for all MS to use and adapt to their specific needs.

#### CHALLENGES

- Support integrated work amongst MS health systems
- Improve access to (mental) health care by focusing on prevention and community based mental health services

#### LESSONS LEARNT

- This action provides MS the opportunity to learn from each other
- It will greatly strengthen the EU by organising a commom response to the increasing mental health challenges.

More information: Koen Lowet, Executive Council, koen.lowet@efpa.eu



### Newborn screening



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### A Pledge for a European Framework on Newborn Screening (NBS)

#### BACKGROUND

"Newborn screening identifies conditions that can affect a child's long-term health or survival. Early detection, diagnosis, and intervention can prevent death or disability and enable children to reach their full potential<sup>1</sup>".

#### Great inequalities among member states (MS) regarding NBS

- Some member states only test for 2 diseases while others test for up to 40<sup>2</sup>.
- Attitudes towards the implementation of NBS differ greatly within & among countries<sup>3</sup>.
- The extension of current national NBS programs are challenging, especially in small countries such as Luxembourg. Small countries do not always have the capacity to organize the test<sup>45</sup>, or to analyse all the samples. Moreover, countries may lack the financial resources<sup>67</sup>, or an appropriate decision making structure (please see more challenges on the second page).
- An EU Framework including an EU Expert Forum on NBS (co-)financed by the EU4Health program could provide assistance to Member States. Such initiative would facilitate cooperation between the MS in areas where such collaboration would have an added value while respecting the principle of subsidiarity8.

#### **IDEAS**

- Create an EU Expert Forum on Newborn Screening
- Create an EU wide Newborn screening framework

# How this will help to strengthen the EU Health policy and enhance the health of European citizens?

- Facilitate cooperation between MS on screening, diagnosis and prevention.
- Contribute to the prevention of non-communicable diseases or their consequences.
- Encourage a better integration of the ERNs into national healthcare systems.
- Emphasize the importance of the Cross-border Health Care Directive.
- Contribute to the implementation of the EU Health Data Space.

#### CHALLENGES

- THE AVAILABILITY OF TREATMENT
- EVERY HEALTH
   SYSTEM IS DIFFERENT
- THE STORAGE OF THE BIO-SAMPLES
- THE REGISTRATION OF THE RESULTS IN A REGISTRY
- THE NATIONAL BIO-ETHICS LAWS
- DECISION MAKING PROCESSES ON MS LEVEL
- THE CAPACITY TO ANALYSE SAMPLES
- LIMITED FINANCIAL MEANS
- THE CAPACITY TO ORGANIZE THE TESTS
- ADAPTED CARE PATHWAYS

### Which contribution to the achievements EU4Health objectives?

#### This action contributes to achieving:

- The strategic objective: 'Strengthen the national health systems'
- Specific objective 4: 'Strengthening the effectiveness and accessibility to health care systems including combating inequality'.
- Specific objective 6: 'Support action for the surveillance, prevention, diagnosis, treatment and care for noncommunicable diseases'.
- Specific objective 9: 'Support the integrated work among member states and in particulier their health systems'

Furthermore, this action would help the EU4Health Program to contribute to the UN sustainable development goal 3: 'Ensure healthy lives and promote wellbeing over the life course'. More specifically this action will contribute greatly to subgoal 3.2: 'End preventable deaths of newborns and underfive children'. And subgoal 3.4: 'Reduce by one-third premature mortality from non-communicable diseases (NCDs) through prevention and treatment, and promote mental health and wellbeing '.

- The EU Expert Forum should be representative of multiple stakeholders concerned by NBS.
- The challenges need to be taken into consideration while setting up this action.
- This initiative should build on the work on NSB in the ERN expert group and the initiatives during the Slovenian and Czech Presidency.
- EURORDIS, has developed <u>11 key principles for Newborn</u> screening<sup>9</sup> which should be considered to improve the impact of this action.



Out-of-hospital cardiac arrest



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#### BACKGROUND

Out-of-hospital cardiac arrest (OHCA) is the 3rd leading cause of death in Europe. Approximately 25° cardiovascular (CV) deaths are due to sudden cardiac death (SCD) in Europe which makes SCD responsible of 8-17% of all deaths. A total of 249,538 SCD cases (95% CI: 155,377-343,719 SCD ci are expected each year in Europe (incidence of 48.6 per 100,000 PY). A total of 343,496 emergency medical services-attended OHCA are expected each year in Europe, with an estimated incidence rate 66.9 per 100,000 PY

#### **IDEAS**

- Awareness campaigns (website for patients, TV, etc) about SCD and cardiorespiratory resuscitation (CPR)
- Compulsory annual courses on CPR at schools
- Promotion of an EU App to alert bystanders volunteers of the occurrence of a OHCA for early initiation of CPR
- Better registries and use of artificial intelligence to improve our understanding of risk factors

#### CHALLENGES

- Local regulations
- Need to collaborate with scientific societies

#### LESSONS LEARNT

- This problem should be tackle from a government approach because individual initiatives will have little impact and poor reach
- Need for a stronger collaboration between EU and Scientific Societies

How this will help to strengthen the EU Health policy and enhance the health of European citizens? Any action on increasing knowledge and favouring early CPR would have an huge impact on OHCA survival given the incidence numbers

Which contribution to the achievements EU4Health objectives?

Venous thromboembolism



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#### BACKGROUND

Venous thromboembolism (VTE) affects people from all walks of life. However, certain factors and situations, including common health determinants, can increase the risk of developing blood clots. Identifying people at high risk of VTE, through systematic risk assessment upon hospital admission, means that they can receive preventative advice and treatment as necessary to avoid developing a blood clot.

#### IDEAS

- Reduced disease burden
- Reduced mortality

# How this will help to strengthen the EU Health policy and enhance the health of European citizens?

Across Europe, there are approximately 544,000<sup>i</sup> VTE-related deaths each year. When accounting for indirect costs, the total costs of VTE have been estimated to be as high as 13.2 billion EUR<sup>ii</sup> each year. Early risk identification and treatment can prevent blood clots, and therefore reduce the likelihood of death and disability resulting from VTE.

#### **CHALLENGES**

- Health promotion and disease prevention
- Enhance access to healthcare

#### LESSONS LEARNT

- Awareness raising
- Data collection

# Which contribution to the achievements EU4Health objectives?

Experience from the UKiii shows that requiring acute providers to conduct VTE risk assessments for at least 95% of inpatients each month led to a decrease of 9% in deaths due to VTE. Introduction of such VTE risk assessments helps to prevent venous thromboembolism — which cannot be prevented solely through lifestyle changes — and encourages healthcare professionals to ensure that their patients can access and benefit from physical and/or medical prophylaxis to avoid developing a blood clot.

#### How can we do better for a greater impact?

Risk assessment alone does not necessarily mean that preventative action will be taken<sup>iv</sup>. As such, healthcare professionals require specific training to re-emphasise the importance of assessing and managing VTE. All health systems should collect consistent, interoperable data on the incidence, mortality, and long-term burden of VTE to assess the effectiveness of prevention measures and facilitate best-practice implementation on VTE risk

Centralized remote monitoring service for patient at high risk of sudden cardiac death



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IDEAS

How this will help to strengthen the EU Health policy and enhance the health of European citizens?

- Background/need: to better understand causes and mechanisms of sudden cardiac death (SCD)
- Solutions: prospective follow-up of huge cohorts of patients at risk (for example, those implanted with an internal defibrillator)
- · Solutions: organize this follow up on a centralized remote monitoring service

CHALLENGES

Which contribution to the achievements EU4Health objectives?

- Identifying patients at risk of SCD
- Preventing SCD occurrence in these patients
- · Enhancing this prevention to the majority of the population

LESSONS LEARNT

- Joining forces and diffusion of solutions at the European level
- Education and prevention directly targeting patients, using media and social media channels (information, scenarios, and tutorials diffused by the EU etc...)
- Larger accessibility to "reanimation weapons", like external defibrillators in public places, "defibrillator drones", and facilitated communication and access to emergency departments...

Screening programmes and early detection of Structural Heart Diseases



STAKEHOLDERS' EVENT 8 July 2022

#### BACKGROUND

A form of cardiovascular disease (CVD), Structural Heart Diseases (SHDs) are structural abnormalities of the heart, typically caused by ageing, that lead to impaired functioning of the heart's valves, walls, muscles, and blood vessels. A degenerative disease, SHD cannot be prevented by primary preventative measures. However, when detected early enough, most SHDs can be treated enabling people to go back to their normal life. An EU4Health supported Joint Action and screening targets to improve early detection of unpreventable CVDs, including SHD, could support Member States to save lives, improve quality of life, whilst improving awareness and data collection.

#### **IDEAS**

- Screening programmes and early detection of SHD would ensure that these conditions are diagnosed early and can be treated accordingly.
- Symptoms of SHD are often mistaken as the normal process of ageing by older people and healthcare providers. This leads to mistreatments and poor health outcomes, when a regular stethoscope check for all people above 65 years old
   followed if needed by echocardiography - could prevent this through a correct
- followed if needed by echocardiography could prevent this through a correct diagnosis. This would positively benefit people's quality of life and reduce the burden on hospitals and the healthcare system as a whole.
- Improve data collection on and access to information on SHD. Digital tools should be prioritised, for example through digital checks, patient registries, and online repositories, to support research, and improve awareness for patients and healthcare professionals.

Joint Action and screening targets for SHD

#### **CHALLENGES**

- Lack of concrete guidelines for SHD screening at the EU and national level.
- Poor data collection on and access to information on SHD.
- Limited data sharing across and between Member States on national best practices and patient experiences.

Facilitate
availability of
data,
awareness
and transfer
of best
practices and
experience.

#### LESSONS LEARNT

- Learning from the experience and organisation already in place for other screening programs (cancer), the EU must take steps to encourage the development of screening programs for CVDs, including SHD, by setting minimum screening targets.
- EU4Health can contribute to reaching the Healthier Together EU NCD Initiative
  objectives, by stimulating the exchange of best practices, data and knowledge
  across and between Member States, as well as with stakeholders to enable
  health authorities to pick initiatives that are best suited to their own healthcare
  systems to tackle SHD.

Early
detection
programs and
targets for
CVDs/SHD can
learn from
experiences
and
organisations
in place for
other
screening
programs and
initiatives

### Raising awareness on healthy lifestyle and prevention



STAKEHOLDERS' EVENT 8 July 2022

#### **BACKGROUND**

EuropeActive is the leading not-for-profit organisation representing the European fitness and physical activity sector that serves nearly 62 million consumers. Our aim is to make more people, more active, more often for their health and wellbeing. We therefore run several projects to encourage physical activity throughout the life course, from children to older adults. One of our goals is also to raise awareness and boost health literacy when it comes to healthy lifestyles and disease prevention.

The many health benefits of physical activity are now well established, as it not only contributes to the prevention of several NCDs, but it also helps to improve mental health. It has been proven that regular exercise is associated with better disease outcomes for cancer treatments and when recovering from COVID-19. It is even estimated that 40% of cancers are preventable, and healthy lifestyles play a crucial role in prevention. Yet, despite these being well-known facts, only 3% of healthcare expenditure is spent on preventive care. Furthermore, collaboration between the health sector and other industries remains limited, although closer cooperation would greatly contribute to reaching more citizens and achieving better results.

It is therefore necessary to further develop initiatives aimed at raising awareness and improving healthy lifestyles by fostering collaboration from all sectors.

#### **IDEAS**

- Organising campaigns (especially on social media) raising awareness on healthy lifestyle and prevention
- Organising events, in schools for instance, to promote healthy choices, physical activity, healthy eating

# How will this help to strengthen EU Health policy and enhance the health of European citizens?

Such events are easy to organise and help to increase individuals' knowledge about their own health and how the choices they make have a concrete impact on their welfare.

These campaigns can enhance European citizens' health as they enable greater awareness and proactivity over one's own wellbeing. Overall, the public is empowered to better manage their health. Additionally, it is important to address health in its prevention aspect and in a clear approach to allow for all citizens to be knowledgeable about their health. Living a healthy lifestyle is achievable if the right information is shared and the necessary behavioural changes are made accessible.

It is therefore of crucial importance that EU health policies finally address this and promote such initiatives, on which citizens can actually act themselves.



Raising awareness on healthy lifestyle and prevention (continued)

#### CHALLENGES

- Ensuring that as many individuals as possible are reached
- Organising comprehensible events, improving health literacy levels

# Which contribution could lead to the achievement of the EU4Health objectives?

This would help to achieve the first general objective of the EU4Health programme, which is to improve and foster health. More specifically, it enables individuals to gain control over their health, be healthier and therefore require less care.

It also contributes to the Europe Beating Cancer Plan, as it has been well established by now that regular exercise helps to prevent several types of cancers and is associated with better outcomes when patients are active during treatment. It is estimated that 40% of cancers could be prevented if the right policies were implemented, which includes living a healthy lifestyle. To reduce the number of cancers, citizens need to be made aware of the impact of their choices.

Ensuring that citizens are better aware of the benefits of prevention, including physical activity, would thus have a very concrete impact by reducing the number of NCDs.

#### LESSONS LEARNT

- Collaborate with all stakeholders, including from other sectors, to reach more people and have a greater impact
- Be creative, add something new to projects and campaigns so they are more attractive to citizens
- Make things easy: to develop health literacy levels, health needs to be made accessible to everyone

#### How can we do better for a greater impact?

It is now proven, and repeated by the WHO, that physical activity has significant health benefits for individuals, both for physical and mental health. It is estimated that at least 8 million deaths per year could be averted if the population was more active. Furthermore, people who are insufficiently active have a 20% to 30% increased risk of death compared to individuals who exercise on a regular basis. Being active therefore has a huge public health impact and is the most cost-efficient policy.

Physical activity promotion would thus have a major impact on citizens, concretely enabling them to gain control over their health, make healthy choices, and enhance their wellbeing.

Yet, to be able to reach such results, it is important that the health sector collaborates with other sectors in order to achieve better results. When it comes to prevention through healthy lifestyles, health stakeholders, including DG SANTE, should work with the sport sector, as well as food and drinks, environment, youth, etc. There are several organisations out there with health expertise although they do not solely work on health, and their input could be valuable as they can help the health sector to reach more individuals.



Joint screening on chronic kidney disease, heart disease, diabetes and hypertension



STAKEHOLDERS' EVENT 8 July 2022

#### BACKGROUND

Early detection in combination with healthy lifestyles is supposed to prevent at least 30% people from developing chronic kidney disease, cardiovascular disease, diabetes and the most frequent cancers. We thus propose a population-based screening program, to detect unhealthy lifestyles increasing the risk for those diseases or patients at an early stage of those diseases, followed by an intervention focused on healthy lifestyles. This program would also seek to develop synergies between different disease areas.

#### IDEAS

Joint screening on chronic kidney disease, heart disease, diabetes and hypertension (in stead of separate screening)

Implement it as structural population screening for groups at risk and people as of age 50, including education on healthy lifestyle. This early detection program would lead to a disease management prog focused on healthy lifestyles and other interventions as required, starting early, therewith potentially preventing or delaying the onset of those diseases and identifying early undiagnosed cases.

#### Possible outcomes

- 1). Preventing people of getting chronic diseases and cancer (since more than 30% of these diseases is lifestyle related and most of these lifesty risk factors are common to many non-communicable diseases).
- 2). Lower care and cure consumption, more productive people.
- 3.) Savings in the health budget, more money to target other goals.
- 4). The general population would become more resistant against other diseases, e.g. infections.

#### CHALLENGES

- Organise co-creation of the design of such a program on EU level
- Workload of GP's
- Different levels of screening (programs) in various EU countries

### Which contribution to the achievements EU4Health objectives? The program has a direct contribution to:

<u>Specific objective 1</u>: Health promotion & Disease prevention <u>Specific objective 6</u>: Strengthen health data, digital tools & services, digital transformation of healthcare Specific objective 8: Development & implementation of EU health

legislation & supporting evidence-based decision making.

<u>Specific objective 9</u>: Support integrated work among MS health systems.

#### LESSONS LEARNT

 Start with defining common ground between connected diseases

#### How can we do better for a greater impact?

This joint screening program would create efficient and effective working methods, which would help reduce the burden of chronic and severe diseases and decrease the number of people who live with such diseases.

In the end, it would also be leading to more resilient health systems because healthier people are better protected against other diseases such as COVID-19.



Mental health & well-being



STAKEHOLDERS' EVENT 8 July 2022

#### BACKGROUND

Mental health and well-being are some of the most important areas that need more attention, particularly after the long-lasting COVID-19 global pandemic that left many mental health consequences for the global community. From ICEERS we propose considering alternative treatment options to improve mental health and well-being of the European citizens such as cannabis and hallucinogenic therapies, and other traditional medicines, which are well established in non-Western countries.

#### **IDEAS**

- Support cannabis and hallucinogen research in the field of mental health and well-being.
- Support qualitative research in the field of anthropology and psychology to generate evidence in these fields.
- Create legal frameworks for the production and supply of these substances based on transparency, reciprocity and human rights.
- Consider traditional medicine treatment modalities as effective and valuable options to improve mental health and well-being.
- Encourage the use of evidence-based traditional and cultural practices for promotion and prevention in mental health.

How this will help to strengthen the EU Health policy and enhance the health of European citizens?

Research into efficient cannabis and hallucinogens treatment in different cultural contexts, and an established legal framework enabling production and access of these medicines will provide new treatment opportunities for people who do not benefit from already existing treatments.

Furthermore, broadening the concept of health and well-being by taking into account traditional medicine from non-Western health systems will offer a more complete understanding of health and illness by including external influences (besides purely biological reasons) involved in it.

Greater collaboration with traditional healers is also one of the objectives of the WHO Comprehensive Mental Health Action Plan 2013-2030.

Mental health & well-being (continued)

#### CHALLENGES

- Lack of efficient treatment options to improve mental health and well-being.
- Low political will to change the status quo in drug policy, to move from a prohibitionist approach to a social justice approach.
- High stigma of cannabis and hallucinogens as dangerous drugs and fear of them.
- Current exclusivity of biomedical approaches to treat mental health problems.

# Which contribution to the achievements EU4Health objectives?

1.Include mental health and well-being as one of the top priorities the EU4Health objectives: would contribute to General Objectives "Improve & Foster health", and specific objectives such as "Health promotion and disease prevention".

2. Support cannabis and hallucinogen research in the field of mental health and well-being. Encourage the use of evidence-based traditional and cultural practices for promotion and prevention in mental health: would contribute to General Objective "strengthen health systems" and specific objectives "enhancing access to healthcare", and "developing EH Health legislation and evidence-based decision making"

#### LESSONS LEARNT

 Research shows that cannabis and hallucinogens, and other traditional medicines may be promising treatment modalities for improving mental health and well-being.

### How can we do better for a greater impact?

Include civil society and relevant NGO organizations into the dialogues and enable them to actively participate in the EU4Health programmes.

Support intercultural dialogue on innovative and community-based, non-biomedical therapeutic practices.

Acknowledging the potential of bridging traditional knowledge and scientific research to implement a safe and fair use of hallucinogens in the European society.



Centralized remote monitoring service for patient at high risk of sudden cardiac death



STAKEHOLDERS' EVENT 8 July 2022

### BACKGROUND

Sudden cardiac death (SCD) is responsible for more than 350 000 deaths in the EU every year. It represents a public health problem with important societal and psychological consequences, and is a large financial burden for health care systems.

### **IDEAS**

### How this will help to strengthen the EU Health policy and enhance the health of European citizens?

By proposing a strategy covering the research, prevention, education and therapeutic fields, based on the objective of fighting against SCD.

- Background: there is a need to better understand the causes and mechanisms of sudden cardiac death (SCD)
- Developing the research through a large European network based on large cohorts of patients known at risk of SCD, continuously followed in real time by remote monitoring
- This network taking base on existing EU public and private research institutions, and research projects already launched like:
  - > DAIPP Consortium, Promotor French National Institute of Medical Research INSERM already > 5000 included and followed real time since > 2 years objective 10 000 patients followed during 10 years
  - > PROFID Consortium, Promotor Leipzig Heart Institute, EU HORIZON 2020 ID: SEP-210574856
- Follow up organized on a centralized international remote monitoring service (i.e.: *Implicity*)



Centralized remote monitoring service for patient at high risk of sudden cardiac death (continued)

### **CHALLENGES**

### Which contribution to the achievements EU4Health objectives?

- Phase 1: Identifying patients at risk of SCD, centralized remote follow-up (i.e. DAIPP...), research network based on these cohorts
- · Diffusion phase 2: Preventing SCD occurrence in patients at risk
- Diffusion phase 3: Enhancing this prevention to the majority of the general population based on 1 and 2

### LESSONS LEARNT

- Joining forces and diffusion of solutions at the European level
- Education and prevention directly targeting patients, using media social media channels (information, scenarios, and tutorials diffused by the EU...)
- Larger accessibility to "reanimation weapons", like external defibrillators in public places, "defibrillator drones", and facilitated communication and access to emergency departments...



One health approach: bridging gaps across sectors to preserve – and improve – the health of humans, animals and the environment



STAKEHOLDERS' EVENT 8 July 2022

#### BACKGROUND

Both current and future health challenges (e.g. antimicrobial resistance, infectious diseases, chemical contaminations) require to bridge gaps across sectors to preserve – and improve – the health of humans, animals and the environment. An example of how to build these bridges is the One Health European Joint Programme (One Health EJP). Launched in 2018 under Horizon2020 and ending in September 2023, the One Health EJP is a partnership across 43 public health, animal health and food safety organisations across 22 European countries, and the MedVetNet Association. It aims to improve preparedness, detection, and response by enhancing collaboration, integration of activities and harmonisation of approaches in the fields of foodborne zoonoses, AMR, and emerging threats.

The solutions recommended by the One Health EJP (under section "lessons learnt") are appropriate for Strand 1: Crisis Preparedness and Strand 2: Health promotion & Disease Prevention.

#### **IDEAS**

- One Health EJP outcomes inform diagnostic and reference laboratories, risk assessors and risk managers, and its readyto-use outcomes are picked up by stakeholders at the national, European and global level.
- The benefit of the One Health EJP lays in the foundation to recognise importance of human health, animal health and food safety - and on the benefits of collaboration across these sectors.

How this will help to strengthen the EU Health policy and enhance the health of European citizens?



One health approach: bridging gaps across sectors to preserve – and improve – the health of humans, animals and the environment (continued)

#### **CHALLENGES**

- One Health is well acknowledged in the overarching EU and global policies. However, legal implementation is scarce or even absent in many countries, and without legal basis operationalisation of One Health is hardly achievable.
- The financing of the One Health EJP consortium will end in September 2023 and only a restricted number of its crosssector activities will be taken over by for instance the Med Vet Net Association, resulting in a loss of established networking and a limited uptake of the EJP outcomes.
- Horizon Europe acknowledges One Health, however One Health initiatives are scattered over different Commission services, impairing a harmonised approach.
- EU4Health intends to implement Horizon Europe solutions for health research. This will fall short without tackling aspects like AMR, infectious diseases and chemical contaminations that occur at the interface of humans, animals and the environment.

Which contribution to the achievements EU4Health objectives?

#### LESSONS LEARNT

- Funding has to be well designed to fully encourage crosssectoral collaborations, not just one sector. We propose two solutions that EU4Health could put forward:
- 1) To enable synergy with Horizon Europe by launching, under EU4Health, a cross-cluster mechanism to bridge between Cluster 1 (Health) and Cluster 6 (Food, Bio economy, Natural Resources, Agriculture and Environment), as well as One Health -related EU4Health activities. This would greatly support implementation of solutions in a One Health fashion.
- 2) To launch a specific, ambitious One Health Action with substantial funding to scale up and support the implementation of cross-sector solutions already started under Horizon2020. One Health networks should be expanded and consolidated in Europe, based on existing successful initiatives, thus gaining maximum impact of the investments made.



### One health approach



STAKEHOLDERS' EVENT 8 July 2022

#### **BACKGROUND**

Well-known current health challenges demand us to bridge gaps across sectors if we want to preserve – and improve – the health of humans, animals and environment alike. A distinguished example of how to build these bridges is the One Health European Joint Programme (One Health EJP). Lunched in 2018 under Horizon2020 and ending in 2023, the One Health EJP is a partnership across 43 public health, animal health and food safety organisations across 22 European countries, and the MedVetNet Association (MVN Association). It aims to improve preparedness, detection, and response by enhancing collaboration, integration of activities and harmonisation of approaches in the fields of foodborne zoonoses, antimicrobial resistance, and emerging threats. Considerable attention is given to the application and impact of developed solutions at the national, European and global level.

#### IDEAS

- One Health EJP outcomes inform diagnostic / Med-Vet laboratories, risk assessors and risk managers, thanks to its well-established links with national, European and international interaction mechanisms. Ready-to-use One Health EJP outcomes and education activities are picked up by stakeholders.
- up by stakeholders.

  The benefit of the One Health EJP lays in the foundation to recognise equal importance to human health, animal
- The financing of this consortium will end in September 2023 and only some activities can be taken over by for instance the MVN Association.

health and food safety.

How this will help to strengthen the EU Health policy and enhance the health of European citizens?



One health approach (continued)

#### CHALLENGES

- One Health is well acknowledged in the overarching EU policies dealing with e.g. public health, animal health and the environment, however legal implementation is scarce/absent.
- Horizon Europe acknowledges One Health, however One Health initiatives are scattered over different Commission services, impairing a harmonised approach.
- EU4Health intends to implement Horizon Europe solutions for health research. This will fall short without tackling other aspects directly or indirectly linked with public health (e.g. animal health, food, environment).

Which contribution to the achievements EU4Health objectives?

#### LESSONS LEARNT

- Without legal basis, operationalisation of One Health is hardly achievable, but a One Health Partnership is not foreseen under Horizon Europe.
- Funding has to be well designed to fully encourage crosssectoral collaborations, not just one sector. One solution would be a cross-cluster mechanism, Cluster 1: Health – Cluster 6: Food, Bioeconomy, Natural Resources, Agriculture and Environment.



### Cross-sectorial action against mental health and neurological disorders



STAKEHOLDERS' EVENT 8 July 2022

#### **BACKGROUND**

In Europe, up to 60% of the population is affected by a brain disorder – mental and neurological alike,1) making them a leading cause of disability and mortality in the continent, with an estimated €800 billion cost to health systems per year (the equivalent to approx. 45% of the annual health budget of Europe). With Europe ageing at an alarming speed, the huge burden of brain health is expected to worsen and some call it the health challenge of the century.

It is no surprise that the Commission has made urgent calls for **cross-sectorial action against mental health and neurological disorders** within the areas of health (Healthier Together), employment (Green Paper on Ageing) and social affairs (European Care Strategy). Meanwhile, the EU is expected to act upon the upcoming *WHO Global Action Plan on Epilepsy & other Neurological Disorders* (2022-2031) in line with its commitment to the UN SDGs and WHO targets.

Hence, for EU4Health to be in position to advance such EU policy priority, **previous funding for brain health must be greatly increased** for ambitious efforts in mental health, **but also for coordinated action against neurological disorders ideally in the form of a Joint Action** involving Member States, and building on the brain research progress and technological breakthroughs driven by European brain actors.

1) European Academy of Neurology (2019). The burden of neurological diseases in Europe [Fact Sheet]. Retrieved from

www.ean.org/fileadmin/user\_upload/ean/ean/research/Fact\_sheet\_about\_neurological\_diseases\_Eu rope\_06112019.pdf

#### IDEAS

- <u>Idea</u>: A Joint Action (JA) for Member States to improve access to brain health status and brain health status tracking tools in primary care settings, to improve the prevention, early diagnosis and linkage to care of brain conditions.
- <u>Added value</u>: Dementia and stroke the two neurological disorders with the greatest burden in Europe – are largely preventable, whereas early diagnosis of high-burden brain conditions is associated with improved treatment outcomes (i.e., Alzheimer, epilepsy, etc.) Such JA would be in line with the EU prioritization of brain health and contribute to the following EU4Health objectives:
- Improve years spent in good health for the ageing population (Objective 1);
- 2. Relieve the huge burden of brain health care for health systems by exploiting untapped opportunities in prevention (Objective 1);
- 3. Help address the neurological effects of 'long COVID' (Objective 2);
- Improve access to innovative health neuro-technologies at primary care settings to meet the rising healthcare needs associated with ageing (Objectives 3 and 7);
- Facilitate the full realisation of the European Health Data Space (EHDS) by making anonymised and safe brain data, including realworld data, available (Objective 6);
- Support the implementation of 'Healthier Together' EU Non-Communicable Diseases Initiative and act on the recommendations of the Green Paper on Ageing and the incipient European Care Strategy (Objective 8);
- Cross-border cooperation between Member States (Objective 9) and facilitate action the EU commitment to the WHO Action Plans on Epilepsy and other Brain-related Disorders.

How this will help to strengthen the EU Health policy and enhance the health of European citizens?

Cross-sectorial action against mental health and neurological disorders (continued)

#### CHALLENGES

- Acute mental health symptoms (i.e., anxiety, depression, stress) often attract more policy attention than the prevention, diagnosis and care of chronic neurological conditions;
- EU efforts in neurology normally take the form of Horizon Europe funding for research yet should be accompanied by funding for projects within the clinical setting led by national health authorities and civil society;
- The EHDS can greatly accelerate the digital transformation of healthcare for the good of patients yet to benefit those with neurological disorders; the EHDS must build on sufficient, standardised and interoperable brain data for which the right tools and technologies as regards brain health status and modeling must be accessible at primary care settings.

Which contribution to the achievements EU4Health objectives?

#### LESSONS LEARNT

- For the EU to significantly reduce the burden of brain health, synergies
  must be made between Horizon Europe funding for brain research and
  EU4Health funding to improve prevention, diagnosis and linkage to care
  for neurological disorders in the clinical setting;
- Previous Joint Actions in neurology (i.e., Act on Dementia) showed how much progress can be achieved against neurological disorders when Member States act in cooperation.
- In the area of brain health, EU4Health funding should target mental health AND neurological disorders. Without coordinated EU-wide action, the burden of neurological disorders will continue to worsen in spite of calls to action by the Commission and WHO.
- The availability of tracking the brain health status and performing brain health prognosis by computational means at primary care settings across the EU is fragmented, hence some Member States are better positioned to tackle the challenge of brain health due to worsen as the EU ages.

### Serious game applications



STAKEHOLDERS' EVENT 8 July 2022

#### BACKGROUND

It meanwhile is well documented that serious game applications contribute to prevention of diseases. This is based on the fact that serious games offer a strong tool for the achievement of a sustainable change in behaviour. It all is based on fogg's behavior change model, the result of motivation, capacity and the appropriate triggers. In particular intrinsic motivation is essential for effective and efficient prevention programmes. a first proof of the effect of serious games was published in 2008, Pamela Cato, A video game improves behavioural outcomes in adolescent and young adults with cancer; a randomized trial, Pediatrics, volume 122, issue 2, august 2008.

In terms of cure, the serious game EndeavoRrx received fda approval for the treatment of and in 2020.

The application of serious games in health care however still lacks serious consideration for wide integration in health care. Amongst others this is based on the misunderstanding that serious games are for fun. for this reason playful intelligence describes better what in essence serious games are playful intelligence is the extension of intrapersonal intelligence and inter-personal intelligence, inter-personal intelligence reflects the interaction between people, like between physician and patient, but also between patients (companions), this is external motivation, which in time will turn into intrinsic motivation, intra-personal intelligence, a process within the human's brains.

#### IDEAS

Prevention programmes usually only reach a limited number of people. By means of playful intelligence and well-designed serious games, a wide range of humans can be reached for the benefit of all.

Motivation for long-term use is achieved by calling on the intrinsic motivation of humans and by separation of objective and motivation. Take as an example Pokémon Go, motivation is to capture monsters, objective is to stimulate physical activity.

Citizen engagement will be stimulated by means of so called citizen science, the contribution of citizens to health science. An example is Stall catchers, with about 50.000 users, a multiplayer application with which citizens contribute to the development of treatments for Alzheimer disease. Another example is Foldit, with 240.000 registered players, a game in which a multitude of players support researchers to fold proteins, amongst others for the treatment of HIV

How this will help to strengthen the EU Health policy and enhance the health of European citizens?



Serious game applications (continued)

#### CHALLENGES.

In game design terms the biggest challenges are:

- The definition of the Moonshot: where do we stand in five years
- · Who are the most relevant stakeholders

How to achieve a 100% commitment and involvement of all stakeholders.

We like to challenge EU4Health to think "without a box". With the use of the expertise of the serious game sector in the field of behaviour change to develop applications to reach a European wide, cross border, public. For this purpose consortia with patient representatives, medical professionals, medical industry, policy makers, government bodies and possible other stakeholders have to be funded and established.

The task of these consortia will be to define the moonshot and based on that to develop applications with the integration of playful intelligence for the purpose of the stimulation of European wide effective, efficient and sustainable prevention programmes.

Another objective will be to develop applications, again with playful intelligence integrated, to activate, stimulate and motivate young adults to work in the healthcare sector

In addition, with the means of citizens engagement, the develop programmes to adapt behaviour in terms of a change in mindset, from sickness and care (cure) to health and wellbeing.

Which contribution to the achievements EU4Health objectives?

#### LESSONS LEARNT

- To define the ultimate triggers for intrinsic motivation
- To apply extrinsic motivation (inter personal intelligence) with the ultimate goal, intrinsic motivation (intra-personal intelligence), amongst other for prevention
- To create citizen engagement by means of citizen science. In this
  matter (big) data collection based on PROM's and PREM's shared
  with companion's (humans with the same sickness/patients like
  me) will enhance faster diagnostics and so shorter and less use of
  healthcare systems. (Artificial Intelligence may be combined with
  playful intelligence)
- To use successful strategies designed for one prevention programme for other prevention programmes
- Last but certainly not least, to get commitment and involvement
  of all relevant stakeholders, for which substantial stakeholders
  analysis is imminent Final note: for planetary health we will
  develop so called nudging strategies with several global medical
  device, pharmaceutical and university partners within the Horizon
  Europe program.



# Strand of action 03: Health systems & Health care workforce

- European Reference Networks
- European fund for countries with low GDP
- A coordinated EU strategy on rare diseases
- EU-level action to promote patient & family involvement in improving patient safety
- Online sale of prescription medicines
- Holistic & integrated care pathways for rare disease
- Promoting universal health coverage & decent work agenda
- Evidence-based healthcare
- Over-treatment in medical assisted reproduction
- Continuity of care for cardiovascular disease patients
- Eradicate inequalities in access to the best possible treatment and care for paediatric cancer
- Primary care role in Europe during COVID-19 pandemic
- Focus on drivers of health equity
- Operating grants for NGOs



### **European Reference Networks**



STAKEHOLDERS' EVENT 8 July 2022

### BACKGROUND

European Reference Networks (ERNs) for rare diseases and complex conditions support continuous new developments and innovations, connections with EU research, and developments are being made to integrate them into national healthcare systems.

### IDEAS

- Health promotion & disease prevention
- Enhance access to healthcare
- Development & implementation of EU health legislation & supporting evidencebased decision making
- Support integrated work among MS health systems
- International health initiatives & cooperation

How will this help to strengthen the EU Health policy and enhance the health of European citizens?

### CHALLENGES

- Language barriers
- Time
- Resources

### LESSONS LEARNT

- Networks can react fast to challenges eg Ukraine
- Reduce adminisrative burden
- Virtual consultation for rare and complex diseases working well

Which contribution to the achievements EU4Health objectives?

Objectives 1, 7, 8, 9 & 10 primarily, and objectives 2, 3, 4, 5 & 6 secondarily.

How can we do better for a greater impact?

ERNs registries operational with all member HCPs adding data

Patients and patient organisations give informed consent to share their data ERN registries used as pilot for EHDS Unlocking new evidence, learning and improvements in care for patients with rare diseases and complex conditions



### European fund for countries with low GDP



STAKEHOLDERS' EVENT 8 July 2022

IDEA: European fund for countries with low GDP to afford (innovative) treatments to equalize health of European citizens

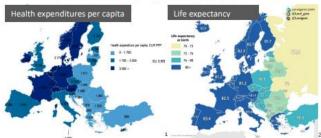
BRINGING MEDICINES TO PATIENTS ALL OVER EUROPE is a common interest of health care systems and industry plus all other involved stakeholders, especially patients.

#### BACKGROUND

Patient access to (innovative) therapies is still varying across Europe, mainly due to economic inequalities. Establishing differential pricing strategies based on GDP are complicated or made impossible by factors like international reference pricing (triggering negative price spirals) and parallel trade. Thus,

- · an agreement on a commercially viable price level cannot be found
- · it is not economically viable to launch innovative products in low GDP countries
- . (future) innovations are at risk when the European market is not attractive

The graphs below suggest a correlation of health expenditures and life expectancy.



In comparison, agricultural subsidies (total budget of 40bn EUR/year) allow all citizens across Europe to afford groceries and in addition strengthen local production.

A similar concept could apply to medicines. Subsidizing the health systems in low GDP countries would enable access to medicines in all EU countries and at the same time.

How will this help to strengthen the EU Health policy and enhance the health of European citizens?

Patients all over Europe will have access to innovative and high-quality medicines. Thus,

QUALITY OF LIFE AND LIFE EXPECTATION WILL INCREASE IN EU!

#### **CHALLENGES**

- Extra fund
- National health care budgets
- Fair distribution

## Which contribution to the achievements EU4Health objectives?

- Enhance availability, accessibility & affordability of medicinal products, medical devices, and crisis-relevant products
  - Enhance access to healthcare
- Support integrated work among MS health systems
- International health initiatives & cooperation

#### **LESSONS LEARNT**

- Healthcare expenditures per capita: 1.292EUR in Romania vs. 4.504EUR in Germany
- Stroke mortality rates<sup>3</sup>: 56/100k in Austria vs. 135/100k in Slovakia
- Ischaemic heart disease mortality<sup>4</sup>: 47/100k in France vs. 381/100k in Hungary
- ... and many more

## How can we do better for a greater impact?

Reduce inequalities between European countries in respect to health care spendings and, thus, health of the population.



A coordinated EU strategy on rare diseases



STAKEHOLDERS' EVENT 8 July 2022

EURORDIS' PROPOSAL FOR A SUCCESS STORY IN EU4HEALTH WP2023:
A COORDINATED EU STRATEGY ON RARE DISEASES

### BACKGROUND

The last rare disease strategy was in 2009 and was largely regarded as a success story, for its role in shaping rare diseases as a public health priority and accelerating European initiatives and national plans on rare diseases. However, since then, science, technology and the policy environment have advanced, and this needs to be revisited.

To "update, adapt or replace" the European rare disease strategy was recommended by the European Court of Auditors in 2019 (Special Report n°7/ 2019), and an EU backed Foresight Study, Rare 2030, saw consensus from different stakeholders that a coordinated framework on rare diseases was essential to see the progress that is needed across the community by 2030. It therefore seems timely for the EU4Health Work Programme 2023 to include a coordinated strategy on rare diseases to align with these recommendations.

Various policy areas related to rare diseases sit under the EU4Health programme, however the area is lacking oversight and direction at the EU level. How has the overall picture for people living changed? How do we want it to change? How is life expectancy improving? How are we connecting data, research, treatment and care?

A rare disease strategy would bring in measurable goals, that do not just fit under one legislative area. Such targets for EU Member States would reduce inequalities that remain across the continent by aligning standards. The strategy would coordinate existing initiatives, drive innovative initiatives, ensuring that the different areas work towards the overall goal to improve the health and wellbeing of everyone living with a rare disease, reducing inequalities, and driving innovation.

### IDEAS

- Coordinate existing or planned initiatives on rare diseases (ERNs, OMP legislation, EHDS, RD Partnership, etc.) under a common strategy
- Include innovative actions such as:
  - Rare diseases as a use case in EHDS
  - Newborn Screening Joint Action to improve diagnosis across Europe
  - An EU Fund to collect Real World Evidence on the effectiveness of orphan products to improve access to treatments
- Bring in measurable goals to track progress of EU initiatives for rare diseases
- Drive national plans or strategies on rare diseases in EU Member States
- An EU multistakeholder advisory group on rare diseases

How will this help to strengthen the EU Health policy and enhance the health of European citizens?

- Strengthen an area of high added value of EU action on RDs: as RD are individually rare, the critical threshold of expertise and patients can only be achieved at EU level
- Address the high levels of unmet needs of the 30 million people living with a rare disease in Europe:
  - 5 years to a diagnosis
  - 95% of rare diseases do not have a treatment
  - Marginalisation from society
- Ensure Member States are mobilised for their rare disease populations: three EU Member States never introduced a national rare disease plan, and several have technically expired policies. The National Plans of nine more countries were due to expire at the end of 2020.<sup>1</sup>
- Bring siloed working of different policies and countries under a coordinated framework for optimisation of costs and maximisation of results for PLWRDs.
- Initiatives that work for RDs are often the blueprint for work in other policy areas.

### A coordinated EU strategy on rare diseases (continued)

### CHALLENGES

- Lack of data on rare diseases at different points of care pathways
- 6000 rare diseases with diversity of experience
- Lack of visibility of rare diseases in national systems
- Varied pace of progress across Europe
- Different EC DGs responsible for different areas: DG SANTE, DG Research and Innovation, DG Grow, DG Employment, Equality and Social Affairs
- Alignment with Europe's Beating Cancer Plan, EU Disability Strategy, EU Pillar for Social Rights

### Which contribution to the achievements EU4Health objectives?

- It would contribute to:
- Specific Objective 1: Through better inclusion of rare adult cancers across Europe's Beating Cancer Plan actions and flagships.
- Specific Objective 3: Through existing work on OMP Regulation, and innovative initiatives on Mechanism of Coordinated Access to OMPs; EU Real World Evidence Fund & EU Cooperation on pricing.
- Specific Objective 6: With strong links to the EHDS and rare diseases as a use case, by creating an ERN test hub for data governance; by building CSO capacity on EHDS; creating a service model virtual crossborder consultations
- Specific objective 7: By improving rare disease diagnosis via European collaboration on Newborn Screening (Joint Action).
- Specific objective 8: By setting EU standards on rare diseases holistically, and through effective CBHC Directive implementation
- Specific objective 9: By continuing to support ERNs and integrate knowledge from ERNs at MS level for RD care; and supporting ePAG participation & financial support in ERNs
- Specific objective 10: By effectively implementing the UN Resolution on persons with RDs in Member States & EU support WHO Global Comprehensive RD Network.

### LESSONS LEARNT

- · We know that:
- Effective policies do not just focus on medicines but on 360° degree needs of PLWRDs
- Holistic and coordinated strategies that break the silos are more effective in responding to the needs of those living with RDs and for healthcare systems (lessons learnt from national and regional plans or strategies for RDs)
- An EU framework is crucial to give impetus to all EU Member States for national frameworks
- DGs and legislation need to be interconnected

## How can we do better for a greater impact?

- Build a framework around existing /upcoming policies and initiatives for greater coherence and coordination across areas.
- Introduce measurable goals & targets to reduce inequalities. Use scoreboard for Member States to keep track of progress.
- Provide increased support towards the improvement of the quality of life of people living with a rare disease and their families and carers.
- Ensure accountability for the 30 million people living with a rare disease through a multi-stakeholder advisory group on rare diseases.

"Our children will be the victims of this lack of coordination. There is a not a 'plan B', a 'life B' for a child living with a rare disease"

Isobel, Belgium, as part of #30millionreasons for European action on rare diseases https://reasons.eurordis.org/



A EU-level action to promote patient and family involvement in improving patient safety



STAKEHOLDERS' EVENT 8 July 2022

### BACKGROUND

The European Patients' Forum (EPF) proposes an EU-level action to promote patient and family involvement in improving patient safety. Patient and family participation is recognised as an important element in prevention of safety incidents and developing a patient safety culture. In past years, projects were funded on patient safety (EUNetPAS, PaSQ) but these did not fully address the issue of patient and family participation. Meanwhile patient safety figures have not drastically improved: an estimated 8-12% of patients are harmed when seeking healthcare.

#### IDEAS

- Understanding of patients/families' role in improving safety
- Enhanced communication and respect for patients, contribution to patient safety culture
- Activating the pan-European patient community, its expertise and networks

How can this help to strengthen the EU Health policy and enhance the health of European citizens?

### CHALLENGES

- Unequal access to high-quality care across Member States
- Prevention of healthcare-associated infections (HCAIs) and antimicrobial resistance (AMR)
- Patchy approaches to patient & family participation, particular challenges in some areas of safety (acute care, aftermath and root cause analysis)

### LESSONS LEARNT, BUT LACK OF IMPLEMENTATION

- Core competencies for patients and families (EPF 2017, based on Council Recommendation 2009/C/151/01)
- Transparent, understandable and comparable information to patients about healthcare quality and safety (2009/C 151/01)
- Gap in understanding to what extent MS health systems actually involve patients and families at different levels, best practices, and their potential for transferability

Which contribution to the achievements of EU4Health objectives?

### Online sale of prescription medicines



STAKEHOLDERS' EVENT 8 July 2022

#### BACKGROUND

#### Online sale of prescription medicines

The EU4Health Programme provides an opportunity for Member States, the EU, and stakeholders to collaborate with the aim to keep European citizens healthy. To this end, as part of the overall programme's objective to ensure availability, affordability, and accessibility of medicinal products, the European Association of E-Pharmacies (EAEP) invites the European Commission to examine the possibility of supporting (e.g. through studies and researches aimed at gathering data) a new action in the 2023 work programme: improving access to medicinal products by making them, especially prescription medicines (Rx), available for patients to order online, regardless in which EU Member State the person lives or orders the Rx.

To date, 24 EU Member States have an e-prescription framework up and running, while six countries foresee the possibility for pharmacies to sell prescription medicine online. In Germany, where the online sale of Rx is allowed since 2004, patients/customers/consumers can order and receive their medication easily at home, leading to enhanced freedom of choice and, therefore, patient empowerment.

At the same time, with the digital solutions offered by online pharmacies – which are not limited to the sale of Rx but rather extended services for medication management as well – patients are constantly provided with a comprehensive online overview of their medication and receive personal advice as to how to deal with their needs/diseases. Such digital solutions, based on safe storage of health data, foster prevention, therapy, and medication adherence.

The manifold advantages of such proven and safe practice are spelled out below.

#### IDEAS

Enabling the online sale of prescription medicines across the EU will help to strengthen the EU health policy and enhance the health of European citizens by:

- Bringing a broad medication portfolio to patients in sparsely populated, structurally weak, and rural areas.
- Ensuring remote expert advice from pharmaceutical consultants to patients who
  e.g. suffer from diabetes and who are not able to obtain such extensive information
  from the local pharmacy.
- Helping patients in tackling their challenges in a proactive way. This includes making use of free online check tools offered by online pharmacies, which provide patients with:
  - Instant comprehensive information on possible interactions between different Rx or between Rx and Over-the-Counter (OTC) drugs;
  - Customised advice on correct usage/application of the chosen medicines;
- Lowering healthcare costs, which are rising year-on-year due to an ageing population and a population which is, despite many efforts, becoming unhealthier (see also recent McKinsey study on respective saving effects in Germany: <a href="https://www.mckinsey.de/news/presse/2022-05-24-42-mrd-euro-chance">https://www.mckinsey.de/news/presse/2022-05-24-42-mrd-euro-chance</a>).

In light of the above, the EAEP would propose a concrete call for tender on a study to set up an EU framework to enhance access to healthcare through the safe online sale of Rx across the EU.

### **CHALLENGES**

- Higher quality of care;
- Greater cost efficiency;
- Improved patient experience;
- Strengthened crisis preparedness and response;
- Optimised work experience for healthcare staff.

#### **LESSONS LEARNT**

• In countries like the Netherlands, Sweden, and Norway, the online sale of medication works perfectly well and complements the healthcare system. Especially the chronically ill and immobile people could appreciate the online sale system, avoiding having to go outside to obtain medicines and be exposed to several threats. Such a system should not be limited to national borders but is in the interest of any EU citizen.



### Holistic & integrated care pathways for rare disease



STAKEHOLDERS' EVENT 8 July 2022

BACKGROUND- EMRADI- EUREGIO MEUSE-RHINE RARE DISEASES.

FINAL REPORT - OF THE EMRADI PROJECT

FACTSHEET- HOW TO GET EU ACTIONS ON RARE DISEASES (RD) CLOSER TO RD PATIENTS AND THEIR RELATIVES? FROM LOCAL AND CROSS-BORDER DEVELOPMENTS TO EUROPEAN SOLUTIONS

### **IDEAS**

- Promoting holistic and care developing integrated care pathways for rare disease patients by taking into account all the needs of people living with a rare disease.
- Developing reimbursement of Telemedicine for
- Structuring coordination RD at EU level and ensuring European solidarity.

### How this will help to strengthen the EU Health policy and enhance the health of European citizens?

Developing local and cross-border solutions for the 35 million persons living with a rare disease in the European Union and their relatives to improve their quality of life close to their home or in the European Union would ensure no patient is left behind and the rarity of a disease isn't cause of further health inequality in the EU.

National-level only approaches are inefficient and ineffective; EU regionaland European-level coordination has a clear added value.

#### CHALLENGES

- Rare diseases do stop borders. European cooperation and coordination rare diseases is essential to allow RD patients access best the expertise available irrespective of the Member States.
- Integrating ERNs in national healthcare systems and developing a framework ensure sustainability and optimal performance these networks.

### Which contribution to the achievements EU4Health objectives?

(d) strengthening health systems by improving their resilience and resource efficiency, in particular through:

(i) supporting integrated and coordinated work between Member States; (ii) promoting the implementation of best practices and promoting data

Article 4- (...)

(f) strengthening the use and re-use of health data for the provision of healthcare and for research and innovation,

promoting the uptake of digital tools and services, as well as the digital transformation of healthcare systems,

including by supporting the creation of a European health data space; (g) enhancing access to quality, patient-centred, outcome-based healthcare and related care services, with the aim of achieving universal health coverage:

i) supporting integrated work among Member States, and in particular their health systems, including the implementation of high-impact prevention practices, supporting work on HTA, and strengthening and scaling up networking through ERNs and other transnational networks, including in relation to diseases other than rare diseases,

to increase the coverage of patients and improve the response to low prevalence and complex communicable and non-communicable diseases.

- Care coordination is a challenge for disease families
- highlighting the need for more patient pathways for RD patients.
- Care costs and care consumptions are higher compared to 'the average' member of health mutual.
- Lack interoperability between information administrative systems hampe European research and policy making.

### LESSONS LEARNT | How can we do better for a greater impact?

- Support cross- border and cross-sectoral projects on rare disease that involve the participation of health mutuals, patients associations that can succeed in making patients centred policy recommendations to improve the quality of life of rare disease patients and their families.
- Develop a European Health Data Space with involvement of all stakeholders and insist on harmonising the coding of RDs.
- Facilitate the mobility of patients with rare diseases by agreeing on an adapted application of the existing European legislation (regulation 883/2004 and directive 2011/24)

### Promoting universal health coverage & decent work agenda

### **IDEAS**

- Turning the human right to health into a reality in the world (mainly in Africa) through projects to extend health coverage to all citizens in a multidimensional way: the role of States, enterprises, social partners, civil society, and the social and solidarity economy, for a universal health insurance scheme.
- Strengthening health systems, both by investing in health infrastructures and in health actors, including mutual health organisations, carrying out actions ranging from prevention and health promotion to curative aspects.

# How this will help to <u>strengthen the EU</u> <u>Health policy</u> and enhance the health of European citizens?

- 1°) Promoting health in all policies, including the articulation between the EU's internal and external policies. The Covid-19 pandemic has highlighted the fact that no one is protected until everyone is protected. All the commitments made in favour of social rights (Future of Europe, European Pillar (Socle) of Social Rights, Action Plan for the implementation of the European Pillar (Socle) of Social Rights, Decent Work worldwide...) must also be applied in the external policy of the Union.
- 2°) Delivering on the commitments undertaken in the partnership between the African Union and the European Union (as well as other regions of the world); and even in times of multidimensional crisis.
- 3°) Carrying forward the **fight against health inequalities** at all levels, cross-border, European and global, making the most of the expertise of European social protection and health actors, including civil society actors such as mutual health organisations.
- 4°) Providing support to civil society and social economy organisations in international solidarity, capitalising on collaboration with European capacity building programmes and global collaboration with the United Nations on multi-actor synergies ("Decent Work and the social and solidarity economy" -, "Universal Social Protection", "Due Diligence" ...).

### **CHALLENGES**

- Promoting universal access to shock-resistant social protection and health coverage and, specifically, fighting against social and health inequalities, as revealed even more by vaccine inequalities, a major challenge for global public
  - health in the face of a "Covid" that knows no borders.
- Establishing health as a global public good. successive crises have reminded us that the world's population does not have access to health care: catastrophic household spendings, ... The European Union has enshrined solidarity in its construction and its values; it includes solidarity, and cooperation, in health, it is the mission of the European commission, as the driving force of the European project, to achieve this.

## Which contribution to the <u>achievements EU4Health</u> objectives?

Contributing to several objectives in a cross-cutting manner.

- 1°) Article 3 (d) strengthening health systems by improving their resilience and resource efficiency.
- 2°) Article 4 (j) supporting global commitments and health initiatives by reinforcing the Union's support for actions by

international organisations, in particular actions by the WHO, and fostering cooperation with third countries.

### LESSONS LEARNT

- For more than 20 years, we have supported the development of the mutualist movement and their cooperation with other health actors (health workers, etc.) as an effective and efficient solution for access to health for the populations, including the most vulnerable... Leaving noone behind.
- So, strengthening
  European initiatives to
  encourage and supporting
  participatory democracy,
  based on social and
  structured dialogue of the
  States with civil society
  and recognising the role of
  social movements and
  social organisations (trade
  unions, mutual health
  organisations, cultural
  organisations).

### How can we do better for a <u>greater</u> <u>impact</u>?

To that extend, we are launching three appeals (calls to action).

a. For a sustainable financing of universal health coverage based on the principles of solidarity, equity and not-for-profit (including a "global social protection fund").

- b. For inclusive and participatory governance to achieve social justice (calling for a coalition of interests between civil society organisations, economic actors, health professionals and States, to achieve universal access to health).
- c. For a concerted and global action around the key points of the "Lomé Platform" (N.B. <a href="https://www.aim-mutual.org/wp-content/uploads/2019/02/18-12-2019">https://www.aim-mutual.org/wp-content/uploads/2019/02/18-12-2019</a> LOME Anglais.pdf)...
- 1. The implementation and strengthening of legal provisions recognising mutual health organisations and the distinctive characteristics of these organisations. These mechanisms must be put in place through implementation measures, thus guaranteeing the viability of mutual health organisations schemes from an institutional, technical, financial, and functional point of view, to develop their full potential to contribute to Universal Health Coverage (UHC).
- 2. The establishment and effective implementation of mechanisms for compulsory enrolment in health coverage for the entire population, based on an evolving process, from design, to transition phases and implementation.
- 3. The management and organisation of the UHC based on a delegation of management entrusted to the mutual health organisations by the State.

### Evidence-based healthcare



STAKEHOLDERS' EVENT 8 July 2022

### **BACKGROUND**

The COVID-19 pandemic brought to light the problems that health systems in the European Union are facing. For persons infected with the SARS-CoV-2 virus, the lack of a single treatment pathway challenged the health workforce. Also, the growing problem of medicine shortages additionally strained hospital pharmacists and other healthcare professionals alike since finding swift solutions to problems caused by medicine shortages is not an easy task and requires considerable time investment on the side of the healthcare professional to find a suitable solution for each individual patient.

Gathering and analysing data in the evidence-based healthcare team played an essential role as outlined by the findings of a <u>Survey on the future crisis preparedness of hospital pharmacies</u> conducted by the European Association of Hospital Pharmacists (EAHP).

To build on the invaluable care that hospital pharmacists provided during the pandemic by finding the best possible solutions to medicine shortages and by compounding medicines to meet patients' needs, EAHP would like to propose an action funded by the EU4Health programme 2023. This action should support the enhancement of evidence-based healthcare across the EU through the expansion of clinical pharmacy services both at the bedside within hospitals and in primary care, fostering collaborative practice among different healthcare professionals and exploring the benefits of pharmacy-based vaccination. For hospital pharmacists, this action should be supported by the competency framework for hospital pharmacy created by EAHP's Common Training Framework project.

**IDEAS** 

How this will help to strengthen the EU Health policy and enhance the health of European citizens?

- The EU4Health programme 2023 should include a specific action to improve evidence-based healthcare. The
  action should address the following shortcomings that were identified by hospital pharmacists during the
  COVID-19 pandemic:
  - Lack of evidence-based decision-making that is also supported by digital health tools
  - Lack of EU-wide evidence-based guidelines for treatment and medicines shortages prevention that improve patient outcomes equally in all Member States
- In addition, the action should build on the problem-solving skills that healthcare professionals honed during the pandemic and also involve them more actively in vaccination campaigns.
- The adaptiveness of the hospital pharmacists and their good sense of crises preparedness should also be further utilised by including a component in the action that would focus on the changing roles of the hospital pharmacy profession and how these could be deployed for offering the best treatment possibilities to EU citizens and patients.



### Evidence-based healthcare (continued)

CHALLENGES

Which contribution to the achievements *EU4Health objectives?* 

An action focused on "evidence-based healthcare" primarily links to

- "Specific objective 3: Enhance availability, accessibility & affordability of medicinal products, medical devices and crisis-relevant products"
  - Giving real-time and on-time information on medicine shortages would help hospital pharmacists to better manage the hospital supply and/or need for compounding as well as to familiarize physicians, nurses and patients with adequate alternatives to reduce medication and/or medical devices errors and have minimal impact on patient safety
  - Providing a risk assessment tool would enable healthcare professionals to apply it in everyday practice and support their evidence-based decision-making
- "Specific objective 8: Development & implementation of EU health legislation & supporting evidence-based decision making"
  - Developing a strategy for better uptake of vaccination and hygiene etiquette in collaboration with all
    healthcare professionals, with emphasis on hospital pharmacists as the profession that is trusted to
    lead the opinions of patients, nurses and physicians, would help improve vaccine hesitance and
    promote evidence-based healthcare
  - Building on the changing roles of the profession by supporting hospital pharmacists in providing more
    input as part of the multidisciplinary healthcare team, would give them and their vital knowledge on
    medicines more visibility as they are very adaptive to new situations and can quickly find evidencebased solutions
- "Specific objective 2: Prevention, preparedness & response to cross-border health threats"
  - Preparing future and present pharmacists together with other healthcare professional
    colleagues for better handling crisis situations through obligatory education as well as utilising
    the competency framework for hospital pharmacy created by EAHP's Common Training
    Framework project across the EU would boost the preparedness of hospitals
  - Changing current practices to allow for more evidence-based healthcare would support the upskilling
    of the healthcare workforce and their digital skills. This would be particularly important for the
    workforce component included in specific objective 2.
- Another challenge identified by EAHP is that the health workforce lacks the capacity for gathering and
  analysing data in the evidence-based healthcare team. This does not only affect hospital pharmacists, but
  also all other members of the multidisciplinary care team working in the hospital. Health workforce shortages
  should be addressed by proposing recommendations for national workforce plans.

### LESSONS LEARNT

- Hospital pharmacists are uniquely positioned for partnering with patients and other healthcare workers due to their engagement in medication therapy recommendations, drug substitution decisions and mitigating adverse effects. Their skills should be better utilised in the future.
- Collaboration is key. Thus, evidence-based decision-making in multidisciplinary teams needs to be fostered, also
  in conjunction with digital health tools EU.
- To address one component of the availability problem, EU-wide evidence-based guidelines for treatment and medicine shortages prevention are needed.



Over-treatment in medical assisted reproduction



STAKEHOLDERS' EVENT 8 July 2022

### BACKGROUND:

### OVERTREATMENT IN MEDICALLY ASSISTED REPRODUCTION (MAR)

- Treatments without proven efficacy, sometimes without proven safety
- · Often paid out-of-pocket, putting a financial strain on patients
- Facilitated by pressure from patients and commercial companies and clinics
- → The European Society of Human Reproduction and Embryology (ESHRE) recommends dedicating EU funding to highlighting and preventing overtreatment

### **IDEAS**

- Develop adequate patient information
- Develop recommendations for proper implementation of innovative treatments, including patient information, data collection and follow-up, out-of-pocket costs

### **IMPACTS**

- > Strengthened patients' rights
- > Improved patient safety
- > Improved quality of care

### CHALLENGES

- Creating awareness among patients and professionals
- Agreement on recommendations between EU Member States



### Continuity of care for cardiovascular disease patients



STAKEHOLDERS' EVENT 8 July 2022

### BACKGROUND

Since 2020, the COVID-19 has heavily impacted society, people and healthcare systems. Today, continued unpredictability and additional sustained healthcare workers shortages as well as unresolved burden on hospitals continues to heavily disrupt access to detection, diagnosis, care and treatment for people suffering from other diseases. Key examples being cardiovascular disease (CVD) - Europe's number 1 killer - and structural heart disease (SHD) - a growing disease burden affecting the ageing population.

**EU public funds** such as EU4Health and Recovery Funds have recognized the importance of strengthening healthcare resilience in a COVID-19 context, and the need to better protect vulnerable populations, such as CVD sufferers and elderly people. EU4Health could support Member States to **invest smartly** and ensure (1) eliminating incurred waiting lists and delays in preventative and elective non-C19 care to allow people to get detected and treated rapidly before it is too late;

- (2) Significantly deploy capacity and efficiency-enhancing innovations that relieve burden on hospitals and improve workforce satisfaction and quality of care; and
- (3) adopt a strategic approach towards hospital preparedness for endemic management by developing surge plans that allow to better manage peaks and troughs in demand for C19 and non-C19 care, that improve hospital efficiencies, capacity, and process.

#### IDEAS

- Improve data collection and monitoring to better anticipate and solve disruptions in access to care for patients, such as CVD treatments, during pandemics.
- Strengthen early detection for at-risk people to allow for earlier treatment and reduce burden on hospital systems
- Support Member States to improve investments and access to innovations, digitalization, and processes that reduce the burden on hospitals and healthcare workers.
- Support Member States to develop surge plans for hospitals during (pandemic) peaks in demand for care
- Reskilling of healthcare professionals and strengthen role of primary care professionals to improve awareness and early detection of CVDs

Invest in continuity of care for cardiovascular disease patients and implement innovation to reduce burden on hospitals and healthcare workers.

### CHALLENGES

- Sustained backlog in preventative and elective cardiovascular care, including structural heart disease, incurred during the COVID-19 pandemic
- Healthcare workers shortages and 'resignation' due to accumulated work burden and disinvestments
- Existing solutions to enhance capacity, efficiency and productivity in hospital and with healthcare workers are not sufficiently deployed.

### LESSONS LEARNT

EU Policy (EU Health Union) and funds (EU4Health and Recovery and Resilience Funds) developed during the pandemic focused primarily on immediate response to COVID-19 without taking an holistic perspective on COVID-19 pandemic for patients suffering from other diseases, such as cardiovascular disease.

COVID-19 Pandemic impact on access to early detection, diagnosis, treatment, and care for patients suffering from cardiovascular disease.

European Health Union and EU4
funds should invest into
pandemic preparedness of
healthcare and hospital systems
to allow for access to care for
patients suffering from
cardiovascular disease

Eradicate inequalities in access to the best possible treatment and care for paediatric cancer



STAKEHOLDERS' EVENT 8 July 2022

### **BACKGROUND**

The European Reference Network on Paediatric Cancer (ERN PaedCan) aims to eradicate inequalities in access to the best possible treatment and care and to ensure that all patients in Europe can benefit from established multi-modal approaches. Among the achievements to date is the development of clinical recommendations & e-training sessions. The EU value-added of ERN PaedCan stems from coordinated approaches achieved in cross-border cooperation in childhood cancer as a rare disease field.

### CHALLENGES

- Financial sustainability
- Cross-border healthcare reimbursement and governance
- Health data sharing and interoperability

### Which contribution to the achievements EU4Health objectives?

Objectives 1, 6, 7, 8, 10: Primary link, and objectives 2, 3, 4, 5, 9: Secondary link

#### IDEAS

- Reduce inequalities of childhood cancer outcomes across all EU Member States
- Equal and possible best paediatric cancer care and outcomes no matter where in Europe children live
- Improve standards of treatment and care for paediatric cancer patients in widening countries
- Roadmap of specialised paediatric oncology centres
- European Standard Clinical Practice guidelines and registry
- Training and educational programmes for paediatric oncologists

How this will help to strengthen the EU Health policy and enhance the health of

European citizens?

ERN <u>PaedCan</u> is a network of the Paediatric Oncology clinical trial community integrating European expertise in the best interest of patients with challenging cancer cases requiring cross-border expert advice at highly specialised sites.

#### LESSONS LEARNT

- Need for sustainable investment into ERN PaedCan
- Need for integration of ERN PaedCan into national health systems
- Need for established rules on compensation and reimbursement of virtual consultations
- Need for clarity on cross-border healthcare reimbursement and governance as well as improved patient access to information

- Invest in the sustainability of ERN <u>PaedCan</u> to further develop its potential and foster its integration into national health systems.
- Contribute to patients' understanding and awareness about their right to cross-border care, including clarity on rules on reimbursement of treatment received outside of one's home country

### Primary care role in Europe during COVID-19 pandemic



STAKEHOLDERS' EVENT 8 July 2022

### **Background**

- Primary Health Care (PHC) treated 85-90% of COVID-19 cases during the pandemic in Europe
- Medical care included SARS-CoV-2 case detection, contact tracing, case management, treatment and monitoring in PHC

### **Ideas**:

- Case detection and testing were performed in PHC in 27/30 European countries.
   25 European countries had hotlines and 6 had also direct access to hospitals.
- RT-PCR and lateral flow test were performed in PHC in 23/30 European countries and free of charge with a medical prescription.
- Mandatory isolation ranged from 5 to 14 days.
- Sick leave was given exclusively by GPs in 21/30 European countries.
- Patient hotels or other resource to isolate were available in 12/30 European countries.
- Follow-up was made mainly by phone call (27/30 European countries).
- Chest X-ray and phlebotomy was performed in PHC in 18/30 and 23/30 European countries respectively
- Ambulatory treatments, including low-molecular-weight heparin and oxygen could be prescribed by PHC in 21/30 European countries if needed
- Indicators regarding PHC COVID-19 activity were not routinely recorded in Europe.

### **Challenges:**

- A need to invest in PHC to disseminate best organizational PHC practices in pandemics and to improve the access to additional testing and ambulatory treatments was found.
- A common policy regarding the number of days of mandatory isolation is needed.
- Multidisplinary teams including PHC and Public Health are needed to face future pandemics
- Self-reported paid leave should be considered to be simplified during future pandemics to reduce bureaucracy and GPs workload
- It is necessary to promote a common legislation in the EU where a series of minimum PHC indicators is included in the ECDC COVID-19 dashboard

### **Lessons learnt:**

- PHC was involved in nearly all steps of COVID-19 medical care in the community, from the suspected cases to the diagnosis and the follow-up and was responsible for the care of the majority of COVID-19 patients.
- Some countries provided all the needed resources to attend patients in the community, however, there were considerable differences amongst countries in the pathways to attend COVID-19 patients and in the available resources.

European

### Focus on drivers of health equity



### STAKEHOLDERS' EVENT 8 July 2022

#### BACKGROUND

Both in the EU and globally, the COVID-19 pandemic has painfully exposed and worsened the pre-existing social and health disparities, impacting the lives of under-served communities. To address health inequalities, it's key to target their underlying in the first place and focus on drivers of health equity. These drivers include policy coherence and strong and transparent accountability frameworks, but also social participation and empowerment of people and communities; this is where public health civil society, with the support of Operational Grants can make the difference.

#### IDEAS

- Strengthen the voice of the unheard
- · Act as a convenor of dialogue
- Empower people, communities and public health civil society organisations

How will this help to strengthen the EU Health policy and enhance the health of European citizens?

- The EU can only deliver on its ambition to be a 'Union of Equality' by listening to the voice of the unheard – through public health civil society – and by developing equitable health policies.
- Civil society convenes stakeholders, builds capacity, and empowers people and communities for more impactful policies on NCDs, for example by addressing cancer inequalities.
- Through amplifying the voice of the unheard, health data will be more harmonised and disaggregated by the factors that visualise inequalities – gender, ethnicity, race, socioeconomic factors – and allow equitable and evidence-informed policies

### CHALLENGES

- Unequal impacts of multiple crises, resulting in health inequalities
- Lack of disaggregated data to provide evidence for decision makers
- Discrimination and stigmatisation resulting in hard-to-reach populations and distrust

#### LESSONS LEARNT

- Co-design with CSOs and vulnerable groups
- Involve CSOs and communitybased groups
- Build synergies with other EU programmes

### Which contribution to the achievements EU4Health objectives?

- The civil society voice leads to more equitable health policies for all, which contributes to improving health across the EU.
- More harmonised, high-quality and disaggregated data will not only reduce health inequalities, but also support the implementation of the EU Health Data Space.
- Targeting discrimination and stigmatisation of vulnerable populations will not only reduce health inequalities, but also increase trust in the EU as an institution.

- Co-design policies with the targeted people and groups leads to more equitable policies, empowered communities, and trust in governments.
- Civil society holds expertise in partnering, forming coalitions, and collaborating with organisations to share competences and increase impact.
- Adapt and implement learnings from EU-funded projects, including H2020 research projects looking at the impacts of COVID-19 on health inequalities



### Operating grants for NGOs



STAKEHOLDERS' EVENT 8 July 2022

### BACKGROUND

Health NGOs are an essential resource in shaping evidence-informed health policy at national and European levels. They can voice the lived experience and needs of patients, healthcare professionals, caregivers, public health professionals and people, therefore contributing to more democratic, accountable, and legitimate policymaking processes. To deliver on their goals, contribute to the EU values, and maintain their independence, health NGOs require a sustainable, accessible, and transparent funding scheme such as Operating Grants (OPGs).

#### IDEAS

- Guarantee the constructive and independent role of NGOs in EU policy processes
- Development of partnerships
- Ensure proximity to EU citizens

How will this help to strengthen the EU Health policy and enhance the health of European citizens?

- Through the implementation of an Operating Grants scheme, the EU Commission would ensure a more balanced, democratic, accountable, and legitimate policymaking processes where health NGOs would be guaranteed to play their constructive and independent role.
- This support would ensure the development of stronger partnerships and facilitate NGOs' contribution with public health expertise to EU health policies. For instance, with non-communicable diseases (NCDs) imposing the highest disease burden in the EU, the return on investment for prevention and care is evident. Coordinating the contributions of stakeholders and bringing good practices and evidence on NCDs in European-level dialogues is a win-win for all actors.
- By guaranteeing a stronger role for NGOs, Operating Grants would further support the implementation of EU health policy initiatives close to EU citizens.

### CHALLENGES

- Health inequalities
- High burden of preventable diseases

### Which contribution to the achievements EU4Health objectives?

- Operating Grants support the involvement of civil society in addressing the socio-economic determinants of health.
- Similarly, they help NGOs in their contribution to disease prevention and health promotion. For instance, EPHA's work on NCDs, and Healthy Environments has provided direct feedback to the EU NCD Initiative.

#### LESSONS LEARNT

- Co-design with beneficiaries
- Add certainty through a multiannual framework agreement
- Support NGOs to respond to external developments

### How can we do better for a greater impact?

- Involving beneficiaries in the design of the grant application system would facilitate planning and reduce administrative burdens for both the EU Commission and NGOs.
- Reinstating multi-annual framework agreements for Operating Grants would provide more certainty and sustainability to health NGOs.
- These elements would enable NGOs to provide permanent support to citizens, including in the response to crises and external developments impacting health and healthcare.

### CONCLUSIONS

EU Operating Grants are the sole financial mechanism that enables health NGOs, civil society organizations and professional and patients' groups to play an independent, constructive, and meaningful role in EU policy processes, and to respond to external developments, while ensuring that the voices of patients and citizens are heard. These activities are key to safeguard the democratic legitimacy of EU's policy processes and to achieve the objectives of the EU4Health programme.

As an example, EPHA's role and advocacy activities in the shaping of the EU NCD Initiative was supported by the Operating Grants. Indeed, bringing our voice to EU policy makers and contributing to a full-fledged EU NCD Strategy is an example of how the OPG creates opportunity for fruitful partnerships between stakeholders to address complex challenges.

- Eco-system tools & interactive services
- Digital infrastructure of hospitals' core activities
- Best practices transfer: responding to and meeting digital needs of citizens/patients enhancing health care provided by professionals



### Eco-system tools & interactive services



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### BACKGROUND

The eco-system E-Platform is the outcome of well-administered EC-funded research and innovation, resulting in a new type of multilingual knowledge management system implemented with the versatile Integrated Management System framework. When combined with the multilingual terminology and cross-lingual information retrieval they form a powerful platform for structured process documentation, compliance management, community building, multilingual communication, smart collaboration and e-Mentoring. The PROMIS® E-Platform (www.promis.eu) is a multilingual, multi-country and multi-client Cloud/SaaS and In-house eco-system of tools and multilingual interactive services, enabling public and private organisations to cut their budgets for compliance management up to half, and decreasing the compliance risks drastically. This is achieved by: (i) Monitoring and controlling legal, external and internal compliance requirements in an integrated way; (ii) maintaining conformity to legislation and supporting evidence-based decisions; Facilitating the understanding of the regulatory environment; (iii) Connecting the islands existing in organizations; (iv) Improving access to users and customers, (v) Improving the relations with regulatory authorities; and (vi) Facilitating certification and audits (Berbenni-Rehm, 2018).

#### **IDEAS**

- EU implementation of health legislation and integrated Compliance, Risk & Governance
- AI-by-Design and Ethics-by-Design

### **CHALLENGES**

- EU implementation of integrated multilingual Compliance, Risk & Governance
- Connecting the "silos"
- Genuine Collaboration
- Improve shared understanding
- Multilingual pre-structured health Big Data,
- Taxonomies, terminologies
- Scalability, interoperability,
- Real-time support
- Different boundary conditions

#### **LESSONS LEARNT**

- Genuine collaboration is still wishful thinking
- Crisis preparedness and response has to be based on shared understanding
- Cross-border healthcare initiatives and global commitments have to be multilingual

### How this will help to strengthen the EU Health policy and enhance the health of European citizens?

- Eco-system tools and interactive services will enable public organisations to cut their budgets for compliance management up to half, decrease the compliance risks drastically and harmonise legislation (European, national, regional, local).
  - Today's AI is growing in quality, but it is often built upon unstructured 'data lakes', which makes it difficult to assess the precision, consistency and therefore the value of the outcomes. To build upon an existing generic framework, structured by humans, for the evidence-based and responsible use of AI, in a way that supports the structuring of (multilingual) knowledge, as well as the management of Big Data, will secure the outcomes that users need and are looking for.

### Which contribution to the achievements EU4Health objectives?

- Obj. 1: Health promotion & Disease prevention
- Obj. 2: Prevention, preparedness & response to cross-border health threats
- Obj. 6: Strengthen health data, digital tools & services, digital transformation of healthcare
- Obj. 7: Enhance access to healthcare
- Obj. 8: EU health legislation's implementation & evidence-based decision making
- Obj. 9: Support integrated work among MS health systems
- Obj. 10: International health initiatives & cooperation

- To build upon what is existing at national levels and connect all on an integrated meta-layered versatile framework, respecting national differences, valuing commonalities and capitalising upon existing European R&D+I results.
- Harmonisation of multilingual taxonomies and terminologies
- Multilingualism at different human-centred levels and layers: scientific, socio-economic, societal, technology, etc.
- To offer trusted multilingual data and interactive services for the evidence-based governance, risk and compliance on a European and global scale with enormous economy of scale.

### Digital infrastructure of hospitals' core activities



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### BACKGROUND

The European Health Management Association (EHMA) has created an alliance advocating to increase the availability of interoperable, digital, medication management systems for hospitals' medication management pathways. Members of the growing alliance include MedTech Europe, the European Patient Safety Foundation, European Patient Forum, European Biosafety Network, European Association of Hospital Pharmacists, European Society of Paediatric and Neonatal Intensive Care, GS1, European Junior Doctors and the European Collaborative Action on Medication Errors and Traceability (ECAMET Alliance).

The ECAMET Alliance includes 21 organisations committed to the formation and promotion of regulations and/or guidelines on medication traceability to prevent medication errors in Europe amongst policy makers within the EU. In order to understand the current situation regarding the extent of digitalisation, systems and actions to reduce medication errors, a pan European survey was conducted in 13 countries as well as with the European Union of Private Hospitals (UEHP). This vital information was included in a recent White Paper and Call to Action entitled "The Urgent Need to Reduce Medication Errors in Hospitals to Prevent Patient and Second Victim Harm".

To create a strong European Health Union, and support a crisis-resistant hospital pharmaceuticals system, it is necessary that the European Union prioritises investments in the digital infrastructure of hospitals' core activities. To ensure that hospitals have adequate stocks of medication a detailed, accurate, medication inventory allowing supply chain managers, hospital leaders, and hospital pharmacists to make informed decisions is required. Digitalisation/electronic medication management (e-prescription, e-preparation, e-administration and e-dispensing of medication) in hospitals is critical to ensure a healthier and safer European Union. Nevertheless, the penetration of digitalisation/electronic medication management in EU hospitals is very low<sup>1</sup>.

### Implications for patients, healthcare professionals and healthcare systems are significant:

### a. For patient safety:

WHO states 1 person per million dies every day from a medication error <sup>2</sup>.

### For health systems and health professionals' resilience:

- Higher risk of experiencing a mental ill-health episode leading to long-term absences from work.
- Medication errors results in delayed discharges and increased bed pressures costing up to 3% of national healthcare budget expenditure.

### c. For combatting AMR:

 Lack of electronic clinical decision support systems can contribute to over, or under, prescribing of antibiotics contributing to the rise of antimicrobic resistance.

### d. For visibility and data on medicine stocks and demand

- Required for the European Medicines Agency European Shortages Monitoring Platform.
- To reduce waste arising from expired medication and the medication compounding process in hospitals.

### e. For continuous, reliable, interoperable data generation:

- Required by the EHDS for primary and secondary data use purposes for both MYHEALTH@EU and HEALTHDATA@EU.
- Transfer, and access, to electronic data from primary to secondary care ensuring continuity of care.
- To ensure data protection for patients and professionals.

### THE IRISH NATIONAL CANCER INFORMATION SYSTEM - NCIS: A SUCCESS CASE SUCCESS ON DIGITALISATION OF MEDICATION MANAGEMENT<sup>3</sup>

The Irish National Cancer Information System (NCIS) is a computerised system that can record information about a patient's cancer case, diagnosis and systemic therapy treatment. The goal of the NCIS is to deliver a clinical information system to support the care of oncology and haemato-oncology patients and digitalisation of medication management is a key enabler of the NCIS.

The platform ensures that all relevant healthcare providers have access to a patient's data in an appropriate and timely manner. In addition, NCIS has several key functionalities which can be used by various health care professionals including prescribing, electronic medication administration records, support for aseptic compounding, multidisciplinary team meetings and medication management. A single deployment makes access to cancer data possible in a standardised way and overcomes many of the barriers associated with a shared record!

The NCIS went live in 2019 and will ultimately be introduced to all 26 public hospitals in Ireland providing cancer services. This project is making a significant difference for patients receiving systemic anti-cancer therapy in Irish Hospitals enabling digital support for prescribing and administering of medicinal cancer treatments.

### Digital infrastructure of hospitals' core activities (continued)

### IDEAS

- Include in EU4Health 2023 one specific program for Member States to invest in electronic medication management systems (e-prescription, e-preparation, e-administration and e-dispensing of medication) for EU hospitals under the digital health strand.
- Since 2021 the digital health strand of the EU4Health programme has been allocated €109 million (the lowest proportion) and all priorities have focused on developing the European Health Data Space. Under the draft EHDS regulation health services, including hospitals, will be required to enter and update common, interoperable, primary data in the European Health Record System for healthcare treatment and delivery thus requiring investments in hardware, software, and staff training.
- Alternatively include this investment under AMR and/or EMA IT platform for crucial medicines shortages platform as part
  of the crisis preparedness strand.
- Or under the health systems and workforce strand under investments in Europe's health workforce and long-term health resilience.

### HOW THIS WILL CONTRIBUTE TO EU4HEALTH OBJECTIVES

### Objective 1: Protecting people in the EU from serious cross-border health threats and improving crisis management capacity

- Improve prevention of AMR as highlighted by the recent 'Hearing of the Expert Panel on Effective Ways of Investing
  in Health on the Opinion Managing antimicrobial resistance across the health system, electronic antimicrobial approval
  systems, e-prescribing and electronic medication Management are some potential digital tools that can support policy
  objectives of tackling and reducing AMR in healthcare settings.
- Improve visibility of stocks and demand of critical medicines for shortages and crisis situations. Currently pertinent not
  only in the COVID context, but also the war in Ukraine given EMA is now 'very closely' monitoring possible medication
  shortages in the EU.

### Objective 2: Making medicines, medical devices and other crisis relevant products, available and affordable and supporting innovation.

- Improve visibility of stocks and demand of critical medicines for shortages' management and crisis situations, to
  generate accurate and real time data on stocks and demand of critical medicines for new EMA shortages database.
- Increase safety of medicines by preventing medication errors in EU hospitals, acting as a preventative measure to
  protect staff wellbeing and ensure health system resilience.
- Increase affordability of medicines by reducing waste from expired medications.
- Data generation on medication treatments in interoperable systems to support research and innovation in new therapies.



Best practice transfer: responding to and meeting digital needs of citizens/patients enhancing health care provided by professionals



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### BACKGROUND

### IDEA

Best practice transfer projects like JADECARE (Joint
Action on implementation of Digitally Enabled
integrated person-centred CARE) intend to
reinforce the capacity of health authorities to
successfully address the transition to digitallyenabled integrated-person-centred care. JADECARE
enables the transfer and adoption of Best
Practices to other regions in Europe according to
their situation and digital needs and maturity. The
project will have an impact on healthcare
professionals, patients, carers, general population,
health authorities and the industrial sector.

How this will help to strengthen the EU Health policy and enhance the health of European citizens?

### CHALLENGES

From the project it becomes evident, that citizens/patients digital needs and skills regarding decisions that affect their health, regarding a say and in the management of their very own health data and regarding an active, intentional digitally-supported dialogue with their healthcare providers is a relevant challenge in many European countries. Best practice examples to enhance the digital capacities and competences can be of quidance in that respect as well.

### LESSONS LEARNT

Best practices transfer to support health authorities/health professionals in their journey of the digital transformation towards efficient and sustainable health care systems has proven in many cases and projects to be successful. An EUwide effort to foster this endeavours bottoms-up from the citzens/patients side, to build their capacities by different tools and person-centred, targeted approaches to make those benefits fully accessible to their understanding, their personal and holistic use and to the benefit for their whole health care team, proving beneficial also for the health care costs of the system, could be advantageous to be developed complementary.

### Which contribution to the achievements EU4Health objectives?

Addressing this challenge could improve and foster the health of EU citizens considerably , enhancing also the compliance of citizens/patients to health care tools, thereby also strengthening the success of Health systems



## Strand of action 05: Cancer

 Clinical trials to support the development of personalised intratumoral radiotherapies for cancers with poor prognosis



## Strand of action 05: Cancer

Clinical trials to support the development of personalised intratumoral radiotherapies for cancers with poor prognosis



STAKEHOLDERS' EVENT 8 July 2022

### **BACKGROUND**

**Europe's Beating Cancer Plan** includes the goal to support efforts to advance personalised medicine, focusing initially on cancers with poor prognosis such as pancreatic or head-and-neck cancers. While the EU has put in place effective funding mechanisms to fulfil the objectives of this milestone Plan, addressing the urgent needs around pancreatic cancer and adequately supporting clinical trials in this field are however not reflected in the EU4Health work programmes.

Nuclear and radiation science and technologies play an important role and provide a wide range of benefits to EU citizens in many areas beyond the production of nuclear energy, in particular in relation to human health. These technologies are indispensable in the fight against cancer and contribute significantly to all stages of cancer patients' care, including early detection, diagnosis, treatment and palliative care. This is why the SAMIRA Action Plan is closely linked and intended as a contribution to the main objectives of the Commission's "Europe's Beating Cancer Plan" initiative. In fact, the activities included in the SAMIRA Action Plan serve one common objective: to ensure that EU citizens have access to high-quality radiological and nuclear technologies in medicine, at the highest safety standards. It states specifically the need to support clinical trials to promote access to high-quality radiological and nuclear technologies in cancer care by funds such as EU4Health.

Some of the most important recent pharmaceutical and clinical developments in nuclear medicine cancer treatment originated in the EU. Modern radiation-based imaging and therapy are constantly progressing, leading to new and improved approaches to diagnosing and treating cancer and other major diseases. This rapid technological innovation is, on one hand, supported by significant private investment in research and development and, on the other, has to respond to the needs of publicly funded health systems across the EU. Issues of public interest, such as quality and safety of medical applications and supply of radioisotopes, are not always commercially attractive and would therefore need public support and significant investment, especially at EU level.

Cancer interventions increasingly rely on novel radiation technology, such as image-guided radiotherapy, proton therapy, targeted radionuclide therapy and hybrid imaging, in order to advance precision and personalised treatments. In its Conclusions on Non-power nuclear and radiological technologies and applications of 2019, the Council invited the Commission to support research on topics related to non-power applications of nuclear and radiological technologies, such as medical applications of ionising radiation. Furthermore, the Council stressed the importance of delivering a research roadmap for medical applications in a timely manner. Improving technology transfer from concept to application through better cooperation between the research community and the industry would also decrease the time required to put products on the market and improve access to innovative treatments across all Member States. As a result, it is evident how the Commission's support for addressing these challenges will maximise the overall impact of the EU research and innovation programmes.



## Strand of action 05: Cancer

# Clinical trials to support the development of personalised intratumoral radiotherapies for cancers with poor prognosis (continued)

#### **IDEAS**

How will this help to strengthen the EU Health policy and enhance the health of European citizens?

(Source: European Cancer Organisation Essential Requirements for Quality Cancer Care (ERQCC): Pancreatic Cancer)

- Addressing the unmet needs around cancer with poor prognosis, including pancreatic cancer.
- Survival for patients with pancreatic cancer is extremely low with a 5-year relative survival rate in Europe between 2000 and 2007 of 6.9% with no trend toward better outcomes. It is reported to be the only type of cancer that has seen no improvement in survival in 40 years.
- Given the present lack of improvement, pancreatic cancer is predicted to become the third leading cause
  of cancer-related deaths in the EU countries by 2025 after lung and colorectal cancers. As if that were
  not enough, funding for pancreatic cancer research has lagged behind other cancers in many countries,
  receiving less than 2% of all cancer research funding in Europe.
- The vast majority of pancreatic cancer patients present with inoperable locally advanced or metastatic tumours (approximately 80–90% of cases), for whom standard treatment is systemic chemotherapy. Though the efficacy of systemic chemotherapy is increasing, the treatment aim is still palliative, a minority of patients with initially inoperable locally advanced tumours may benefit from treatment-induced downstaging and become candidates for a potentially curative surgical approach.
- In light of the above, researching and advocating for effective treatment options must be a priority if we are to improve upon the very low survival rate of patients with (locally advanced) pancreatic cancer. In this regard, personalised intratumoural radiotherapies have the potential to treat patients with locally advanced cancer. With these personalised therapies, tumours could be reduced in size to make surgical resection possible which could then considerably increase the survival of these patients. New personalised treatments have therefore the great potential to restore standard treatment options for pancreatic patients.
- We propose for EU4Health WP 2023 to include funding of clinical trials to support the development of personalised intratumoral radiotherapies for cancers with poor prognosis. This is because the development of radiotherapies and personalised medicine clearly fit under the goals of the SAMIRA Action Plan as well as the Beating Cancer Plan.

#### CHALLENGES

Which contribution to the achievements EU4Health objectives?

- This would contribute to Specific Objective 1: Health promotion & Disease prevention and in particular Increasing quality of cancer care, by addressing cancers with poor prognosis including pancreatic cancer.
- It would also contribute to Specific Objective 3: Enhance availability, accessibility & affordability of medicinal products, medical devices and crisis-relevant products, especially in the context of boosting the implementation of the SAMIRA Action plan.



# Thank you!

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