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POLICY DEPARTMENT
ECONOMIC AND SCIENTIFIC POLICY **A**

Economic and Monetary Affairs

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Limits and Potentials of the Public Health Programme

Study for the ENVI Committee



DIRECTORATE GENERAL FOR INTERNAL POLICIES
POLICY DEPARTMENT A: ECONOMIC AND SCIENTIFIC POLICY

WORKSHOP

Limits and Potentials of the Public Health Programme

Brussels, 22 November 2017

PROCEEDINGS

Abstract

This document summarises the presentations and discussion taking place at the workshop organised by Policy Department A on the limits and opportunities of the Third Public Health Programme, held at the European Parliament in Brussels.

The aim of the workshop was to inform the Members of the ENVI Committee and all participants on the limits and potentials of the Public Health Programme, and to have an overview of the outcomes and impact the Third Health Programme had for EU institutions, Member States and individual organisations/projects in its first half (2014-2017).

Firstly, the institutional perspectives from DG SANTE and Chafea were presented. The results of the mid-term evaluation of the Programme were discussed, both emphasising the overall positive result of the evaluation and highlighting the areas of improvement and lessons learnt from the two previous health programmes. Next steps to overcome the current limits were also outlined. Secondly, the focus was on the experience of Member States, which confirmed the value of the Programme for their National contexts, insisting, however, on the need to increase the available budget in order to achieve the targeted objectives. Finally, presentations were given by organisations and projects that have successfully utilised funds from the Health Programme.

This document was requested by the European Parliament's Committee on Environment, Public Health and Food Safety.

CONTRIBUTING EXPERTS

MEP Ms Soledad CABEZÓN RUIZ, Co-Chair ENVI Health Working Group

MEP Mr Alojz PETERLE, Co-Chair ENVI Health Working Group

Ms Irene ATHANASSOUDIS, Policy Officer, DG SANTE

Ms Donata MERONI, Head of Health and Food Safety, Chafea

Mr Jean-Baptiste ROUFFET, NFP France, Conseiller Affaires Européennes, Mission des Affaires Internationales et Européennes. Direction Générale de la Santé, Ministère des solidarités et de la Santé

Ms Sarah COLLEN, NFP UK, Senior Policy Manager, NHS European Office

Ms Mirca BARBOLINI, Project Coordinator, SUNFRAIL

Ms Valentina BOTTARELLI, Public Affairs Director, Head of European and International Advocacy, EURORDIS

SUMMARY PREPARED BY

Ms Mariana DATES (Optimity Advisors, London, UK)

Ms Micol TEDESCHI (Optimity Advisors, London, UK)

RESPONSIBLE ADMINISTRATOR

Dr Miklós László GYÖRFFI, Parliamentary Research Administrator

EDITORIAL ASSISTANT

Eva ASPLUND

ABOUT THE EDITOR

To contact the Policy Department or to subscribe to its monthly newsletter please write to:

Policy Department Economic and Scientific Policy

European Parliament

B-1047 Brussels

Poldep-Economy-Science@europarl.europa.eu

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LIST OF ABBREVIATIONS

3PHP	Third Public Health Programme
Chafea	Consumers, Health, Agriculture and Food Executive Agency
DG SANTE	Directorate General for Health and Food Safety
EC	European Commission
EFSI	European Fund for Strategic Investments
ENVI	Committee on the Environment, Public Health and Food and Safety of the European Parliament
EP	European Parliament
ESIF	European Structural and Investment Funds
EU	European Union
GNI	Gross National Income
H2020	Horizon 2020
HYL	Healthy Years of Life
JA	Joint Actions
MEP	Member of the European Parliament
MS	Member States
NCD	Non-Communicable Diseases
NFP	National Focal Point
NGO	Non-Governmental Organisation
OPC	Online Public Consultation
SMART	Specific, Measurable, Achievable, Realistic and Time-bound
SRSP	Structural Reform Support Programme
SWOT	Strengths, Weaknesses, Opportunities and Threats
TB	Tuberculosis
ADs	Autoimmune Diseases

EXECUTIVE SUMMARY

On Wednesday 22 November 2017, the Health Working Group of the European Parliament Committee on the Environment, Public Health and Food Safety (ENVI) held a workshop entitled *“Limits and Potential of the Public Health Programme”*. The workshop was chaired by MEP Ms Soledad CABEZÓN RUIZ and MEP Mr Alojz PETERLE. Representatives from DG SANTE, Chafea, National Focal Points (NFPs), NGOs and funded programmes discussed outcomes of financed actions, use of resources, areas of improvement, and difficulties in accessing the Programme.

Ms Cabezón Ruiz stated that the workshop was an opportunity to scrutinise the implementation of the Third Public Health Programme (3PHP) to better understand its impact and to analyse areas for improvement. She emphasised the significance of the 3PHP as the key tool to implement EU-wide health strategies, foster synergies between Member States, and support national health policies. She underlined the relevance of the 3PHP in the current socio-economic context, where countries aim to reach universal health coverage with limited budgets.

Mr Peterle stressed the importance of the change in focus of the 3PHP and compared it to the previous two Health Programmes: while the priorities of the programme remained similar, the perspective changed from seeing health related issues as a cost, to seeing them as an investment for EU’s growth, sustainable development, and meeting the objectives of Europe 2020.

The first panel opened with the presentation by Ms ATHANASSOUDIS, Policy Officer at DG SANTE, who focused on the results of the Mid-Term Evaluation of the 3PHP¹, and looked into new approaches shifting from the creation of best practices to their practical implementation. The overall conclusion of the evaluation was positive, with the programme being recognised to be relevant to health needs and with strong EU added value. Ms Athanassoudis also described three major lessons learnt: to be consistent and focused on the set priorities; to strengthen and build links with wider EU health policy agenda; and to be explicit on the ways in which actions can add value to the EU.

Ms MERONI, Head of Health and Food Safety Unit of Chafea, focused on the five main areas of improvement highlighted in the mid-term evaluation: refine EU added value; develop a strategy to increase participation from low-GNI countries; improving use of monitoring programmes; using monitoring indicators; and improving dissemination of results. She then explained the measures Chafea and DG SANTE need to implement to overcome these limitations. Ms Meroni referred to actions to simplify the complex procedure and administrative tasks, the use of new e-tools to manage grants, databases of projects, coordination of National Focal Points networks, and better use of dissemination platforms (e.g. web, seminars, tutorials, etc.).

Mr ROUFFET, the France NFP representative, opened the second panel by presenting the French national perspective of the 3PHP. He stated that the objectives of the 3PHP are tightly aligned with Member States priorities and perspectives, and highly valued the European community and synergy of health professionals facilitated by the 3PHP. However, Mr Rouffet emphasised the need for a more consistent budget to ensure that the objectives can be met.

Ms COLLEN, the UK NFP representative, referred to the 3PHP as “a small programme with big EU value” and stated its importance in relation to national public health initiatives. She

¹ Available from: https://ec.europa.eu/health/programme/policy/2014-2020/midterm_evaluation_en

highlighted the role of the Programme in crisis management (e.g. in response to the Zika Virus and Ebola pandemics) and in the development of collaborative research. She also spoke about the requirement for more significant funding to ensure that actions have the impact required.

At the start of the third panel, Ms BARBOLINI spoke on the success story from the SUNFRAIL project, funded by the 3PHP. To address current challenges such as an ageing population, and consequent increase in the prevalence of frailty, chronic diseases, and multi-morbidities, SUNFRAIL has developed a 9-questions tool to prevent and manage frailty. The SUNFRAIL tool has already been integrated with health, social and community services in Emilia-Romagna, and its adoption has now been requested in various countries across the EU.

Ms BOTTARELLI, representing EURORDIS – Rare Diseases Europe (a non-profit alliance of over 700 rare disease patient organisations), focused on the Operating Grant that has funded a part of many of their core activities for years. Ms Bottarelli stated that the Operating Grant, received since 2009, has been used to build the patient community, raise awareness of rare diseases in Europe and provided financial stability to the NGO. Ms Bottarelli, however, also expressed a strong sense of instability felt at the end of each financial year, due to the timeline of decision-making processes to renew the Grant.

Mr Peterle MEP concluded the session by re-stating the importance of the 3PHP in changing working structures to increase cooperation and synergies across various actors. Mr Peterle also highlighted the urge to further promote the 3PHP to increase its status among MEPs, and to advocate for higher funding in the next cycle.

LEGAL AND POLICY BACKGROUND

The EU Public Health Policy

The EU public health policy has a complementary, coordinating and supporting role for its MS in regard to the protection and improvement of EU citizens' health. While national governments have the duty to develop, organise and set goals for their healthcare systems, the EU helps MS to reach shared goals (e.g. healthier lives) and to tackle shared challenges (e.g. reduce prevalence and incidence of diseases, prevent pandemics)². The EU health policy, implemented through the Health Strategy, is legally supported by the Treaty on the Function of the EU (art 168) and the Charter of Fundamental Rights of the European Union (art 35), and it focuses on prevention programmes, on e-health and technological innovations, and on reducing health inequalities³. It is based on four core principles:

- Universal health values.
- Health as a major form of wealth, key driver for EU's economic growth.
- Inclusion of health in all policies, in order to have a holistic approach across all fields.
- Strengthening of the EU's voice in the field of global health.

One of the ways in which the EU financially and politically supports MS's governments to improve their population's health is through the Public Health Programme.

The EU 3rd Health Programme (2014-2020)

The 3PHP "Health for Growth" was developed as a response to the European governments' need to reform their healthcare systems to keep up with the demographic transition and deficiency of resources⁴. In line with the goals of Europe 2020 to support Europe's sustainable growth, the 3PHP aims to strengthen the connection between economic growth and a healthy population, while maintaining a clear focus on adding value to the EU. By supporting the efforts of MS to increase their population healthy years of life (HYL), the 3PHP will contribute to the goal set by Europe 2020 to have 75% of the working age-population employed, and avoid early retirement due to illness by 2020⁵.

At the core of the Health for Growth programme there are the improvement of EU citizens' health, the development and commercialisation of technological health innovations, and the improvement of interoperability systems to allow further cooperation between different national governments. With a budget of EUR 449.4million, the target of the programme is to support MS to react to the challenges posed by the demographic transition, and to enable citizens to stay healthy for longer, by focusing on four objectives⁶:

² EU Health Policies: Health Strategy. https://ec.europa.eu/health/strategy/policy/2008_2013_en [Last Accessed 22/09/17].

³ The Lisbon Treaty: Article 168. <http://www.lisbon-treaty.org/wcm/the-lisbon-treaty/treaty-on-the-functioning-of-the-european-union-and-comments/part-3-union-policies-and-internal-actions/title-xiv-public-health/456-article-168.html> [Last Accessed 22/09/17].

⁴ European Commission, (2011) Proposal for a regulation of the European Parliament and of the council on establishing a Health for Growth Programme, the third multi-annual programme of EU action in the field of health for the period 2014-2020, COM(2011) 709 final, Brussels, 09/11/2011.




⁵ EU health programme 2014-2020. https://ec.europa.eu/health/programme/policy/2014-2020_en [Last Accessed 22/09/17].

⁶ Chafea: Health Programme. <http://ec.europa.eu/chafea/health/> [Last accessed 22/09/17].

1. Promote health: Prevent diseases and promote healthy lifestyles and good health through the use of cost-effective preventive measures directly tackling major risk factors (e.g. smoking).
2. Protect citizens from serious cross-border health threat: Develop common coordinated strategies to prepare MS's citizens from transnational health threats and pandemics.
3. Sustainable health systems: Identify and develop tools and mechanisms at EU level to address shortages of resources, both human and financial, and facilitate the voluntary up-take of innovation in public health intervention and prevention strategies.
4. Better and safer healthcare: Improve access to healthcare and health information for EU citizens across MS' borders.

Under the 7 year-long 3PHP, the available budget is distributed yearly, through three different funding instruments: projects, Joint Actions (JA) and operation grants, as described in *Table 1*:

Table 1: Funding Instruments of the 3rd Health Programme

Projects ⁷	Joint Actions ⁸	Operation Grants ⁹
Supporting MS in mainstreaming health promotion and disease prevention in health and educational settings.	Supporting actions with clear EU added value, co-financed with MS authorities (60% or 80% EU contribution)	Finance the running costs of an entity that is working in the general European interest, or on an objective that forms part of an EU policy
		
Increase the commitment of public authorities to public health. Communicate the potential of health promotion and disease prevention in MS	Foster cooperation between MS to improve health policies that benefit citizens	Award contribution of third parties carrying out external aid activities

The 3PHP has a robust institutional framework. The EP is the central decision-making institution, and is directly informed by the European Commission (EC) about the outcomes, costs and evolutions of actions under the programme¹⁰. Among the EP duties in the health sector, there are the establishment and advancement of a coordinated public health policies across the EU¹¹. The 3PHP is managed by the EC and is implemented by the Consumer, Health and Food Executive Agency (Chafea), which is in charge of publication

⁷ Chafea: Projects <http://ec.europa.eu/chafea/health/projects.html> [Last accessed 22/09/17].

⁸ Chafea: Joint Actions <http://ec.europa.eu/chafea/health/actions.html> [Last access 22/09/17].

⁹ European Commission: International cooperation. https://ec.europa.eu/europeaid/funding/about-grants/grants_en [22/09/17].

¹⁰ European Commission https://ec.europa.eu/health/sites/health/files/programme/docs/prop_prog2014_en.pdf [Last accessed 22/09/17].

¹¹ European Parliament. Public Health http://www.europarl.europa.eu/atyourservice/en/displayFtu.html?ftuId=FTU_5.5.3.html [Last accessed 22/09/17].

calls, contracting, dissemination, evaluation and monitoring of the programme¹². DG Health and Food Safety (DG SANTE) is responsible for the inputs from MS, development of the annual programmes' priorities and internal communications, while NFPs are essential for the promotion and dissemination of results of the 3PHP at the national level¹³. There are 32 national focal points (from the 28 MS, plus Norway, Iceland, Serbia and Moldova), who represent their national health ministries, assisting Chafea with the implementation and dissemination of the 3PHP at national level, and providing information back on the impact of the programme in their respective countries¹⁴.

Issues and potentials of the EU Public Health Programme

The 3PHP aims to address a number of shared health issues which are on the agenda of all or most MS. Current health challenges faced by European governments include threats for the financial sustainability of healthcare systems (due to ageing population requiring care for longer, costly technologies and rising patients' expectations); shortage of human resources; need to improve patients' safety; need to improve prevention of non-communicable diseases (NCD); need to increase HLY, as life expectancy has increased in an unparalleled way in the past decades; increase in health inequalities within and between MS; and transnational health threats¹⁵.

The "Health for Growth" programme drew on the challenges faced and on the results achieved by the 1st (2003-2007) and 2nd (2008-2013) Health Programmes. For example, the first two Health Programmes worked on an extensive number of isolated vertical activities, targeting each health determinants and disease separately from all others. The evaluation of the programmes reported that the number of activities was too extensive, targets were not always achievable, and not all EU states were involved. As a consequence, the 3PHP has set operational and tangible SMART objectives, the number of activities have been reduced to the ones that can be carried on in the majority of MS, and activities that have the highest impact in increasing efficiency and maximising results at the EU level were prioritised. Moreover, a consistent monitoring and evaluation system was set-up, to allow regular reporting and sharing of data, information and results among involved stakeholders and policymakers¹⁶.

In the Open Public Consultation (OPC) - undertaken from November 2016 to February 2017, stakeholders expressed their opinions and views on the 3PHP. The majority of participants highly supported the programme and agreed on the set goals and objectives. The main concerns lied on the administrative burden and on funding arrangement. A third important challenge identified was the need to improve the dissemination of the results of activities and projects funded by the 3PHP, issue that was also highlighted in the evaluation of the 2nd Health Programme¹⁷. In the Mid-Term evaluation report, it was suggested that better dissemination of knowledge could be achieved by utilising less of the traditional

¹² European Commission: Implementing the 3rd Health Programme https://ec.europa.eu/health/sites/health/files/programme/docs/ev_20141104_co2_en.pdf [Last accessed 22/09/17].

¹³ European Commission Factsheet: 3rd Health Programme 2014-2020. http://ec.europa.eu/chafea/documents/health/hp-implementation-sante-chafea_en.pdf [Last accessed 22/09/17]

¹⁴ http://ec.europa.eu/chafea/health/national_focal_points.html

¹⁵ European commission, (2011). Commission staff working paper: impact assessment, SEC(2011) 1322, Brussels.

¹⁶ European Commission https://ec.europa.eu/health/sites/health/files/programme/docs/midtermevaluation-3hp_opc-summary.pdf [Last accessed 22/09/17].

¹⁷ Mid-term evaluation of the Third Health Programme (2017) file:///mid-term-evaluation-of-the-third-health-programme-2014-2010.pdf [Last accessed 22/09/17].

dissemination means (e.g. conferences), which only target small audiences, to shift towards more fact sheets, for example, in order to reach more people¹⁵.

As part of its legislative responsibilities in the area of health, the EP needs to give a positive vote to the EU's Health Programmes before entering into force. According to the EP, the Parliament and, within it, the ENVI committee, have consistently promoted the establishment of a coherent public health policy, as well as pursuing to strengthen and promote health policy through opinions, studies, debates, written declarations and reports on a wide range of health issues¹⁸. In 2016, the EP published a report, based on the Eurobarometer survey, highlighting the expectations that EU citizens have from EU policies¹⁹. As mentioned before, with its budgetary limitations, the Public Health Programmes are the main means through which the EU contributes to the promotion of health in Europe, but, according to the Eurobarometer survey, almost two thirds of citizens would value a bigger involvement of the EU in the fields of public health and healthcare²⁰. The public interest and support for EU spending and involvement in public health has been consistently growing since 2008. With the new European budget cycle approaching, and the Mid-Term evaluation recently published the Parliament has timely taken stock of the current Health Programme by holding the workshop.

¹⁸ European Commission: Report from the commission to the European Parliament, the council, the European economic and social committee and the committee of the regions.
https://ec.europa.eu/health/sites/health/files/programme/docs/ex-post_2nd-hp-2008-13_comm-report_en.pdf [Last accessed 22/09/17]

¹⁹ Briefing: Public expectations and EU policies. Health and social security (2016)
[http://www.europarl.europa.eu/RegData/etudes/BRIE/2016/583865/EPRS_BRI\(2016\)583865_EN.pdf](http://www.europarl.europa.eu/RegData/etudes/BRIE/2016/583865/EPRS_BRI(2016)583865_EN.pdf) [Last accessed on 22/09/17]

²⁰ Special Eurobarometer 327. 'Patient safety and quality of healthcare
http://ec.europa.eu/public_opinion/archives/ebs/ebs_327_en.pdf) [Last accessed 22/09/17]

PROCEEDINGS OF THE WORKSHOP

1.1. Introduction

1.1.1. Welcome and opening

MEP Ms Soledad CABEZÓN RUIZ, Co-Chair, ENVI Health Working Group

Ms CABEZÓN RUIZ opened the workshop by welcoming the audience and thanking the speakers and the Secretariat for their work in supporting the organisation of the workshop. She noted that health is a necessary condition for development and sustainable growth, and in this regard, the 3PHP was welcomed and approved in 2014, as a way for health to contribute to the objectives of Europe 2020, specifically for the areas of employment, innovation and sustainability. The 3PHP is the key tool for European action to deliver EU added value and to make a real difference to MS. Although health policy is a responsibility of national Governments, the 3PHP is a complementary tool to support the action in areas where cooperation at EU level is either necessary or provides important added value. She stressed the relevance of the 3PHP in the current socio-economic environment in which cooperation between MS is particularly important, because of the shared public health challenges (*i.e.* multi-morbidities, epidemiological transition, demographic transition, etc.), financial challenges (*i.e.* growing healthcare expenditure with reduced budget), and growing patients' expectations. In this context, Ms Cabezón Ruiz emphasised the need for the 3PHP to focus on technology, good practice guidelines and on the promotion of innovative changes to foster prevention.

MEP Mr Alojz PETERLE, Co-Chair, ENVI Health Working Group

Mr PETERLE also welcomed the speakers and attendees and thanked them for their participation. He affirmed that the EU 3PHP, although relatively minor in terms of magnitude, has an important impact and global resonance. The key element of the programme is the formation and maintenance of a strong EU-wide health professional network to share knowledge and experiences. Mr PETERLE considered that the current Health Programme shared similar objectives to the first two, but that compared to the first two programmes, in the 3PHP the perspective has changed, and health is seen as an investment, rather than a cost. He emphasised the need for the 3PHP, with its limited budget, to serve the best interest of MS and other stakeholders. He suggested that the workshop, aiming to address the limitations and potentials of the 3HP, is an important and extremely valuable means to ensure that priorities are aligned with real needs, and that the outcomes from the programme fulfil public's expectations.

1.2. Part I: Institutional Panel Focused on Lessons Learnt from the Health Programme

1.2.1. DG SANTE

Ms Irene ATHANASSOUDIS, Policy Officer, DG SANTE

Ms ATHANASSOUDIS took the audience through the main findings and results of the Mid-Term Evaluation of the 3PHP, published in 2017, discussing the institutional objectives with a focus on the limitations of the programme, lessons learnt from the previous programmes and areas of improvement. She began by defining the four objectives of the

programme (supporting health and preventing diseases; protecting the population from cross-border health threats; improving health systems in innovative ways; and providing better access to healthcare), and summarising the budget allocation across the objectives and horizontal interventions for the 539 actions commissioned in the first half of the 3PHP. She then summarised the structure of the thematic priorities, outlining the 10 priorities that received the highest budget.

Ms Athanassoudis then presented the results of the Mid-Term Evaluation, which was carried out by external evaluators between May 2016 and June 2017. The evaluation, done using both qualitative and quantitative methods, analysed 29 actions. The overall conclusions drawn from the results of the evaluation and of the OPC were that the 3PHP is relevant to current health needs, with clear objectives and effective management of the programme. Moreover, efficiency, added EU value and the administrative burden were significantly improved compared to the previous programmes.

Ms Athanassoudis highlighted the main achievements of the 3PHP. These include the establishment of 24 EU reference networks of rare diseases; the support of MS to increase their capacity-building to respond to cross-border health threats (e.g. Ebola); the contribution to the EU's migration policy by supporting MS to respond to the refugee crisis; and the transfer of knowledge and implementation of best practices in regard to chronic diseases, HIV/AIDS and TB prevention, cancer screening and alcohol harm reduction; uptake of innovation in public health strategies. She then focused on the lessons learnt from the previous health programmes. The first one is to maintain the focus on thematic areas of strong EU added value until the end of the programme. The second one is to strengthen and build links between the programme and the wider EC and EU policy agenda, to maximise both visibility and impact. Finally, DG SANTE suggests spelling out how EU added value can be generated in practice.

1.2.1. Chafea

Ms Donata MERONI, Head of Health and Food Safety Unit, Chafea

Ms MERONI focused her presentation on some of the limits of the 3PHP highlighted in the Mid-term Evaluation and on new approaches focused on implementation, as opposed to the creation of best practices, and on improvements to simplify procedures in relation to the 3PHP. She firstly provided an overview of the role of Chafea as an executive agency. Chafea has two main functions for the 3PHP. Firstly, it is in charge of its management and implementation by organising the publication of calls, final payment of actions, and evaluation of results. Secondly, it acts as the knowledge hub of the programme, collecting data from the various actions carried out, and generating best practice guidance, to feed back into DG SANTE's policy cycle. Chafea is also responsible for the coordination of the NFP network.

Ms Meroni outlined the five main areas of improvement highlighted in the Mid-Term Evaluation: refine EU added value; develop a strategy to increase participation from low-GNI countries; improving use of monitoring programmes; using monitoring indicators; and improving dissemination of results. She then explained the measures Chafea and DG SANTE need to implement to overcome these limitations.

Firstly, to better explain to applicants and to the evaluation panels what demonstrates EU added value, the Mid-Term Evaluation suggested to re-group and simplify the seven criteria that currently characterise "EU added value", to just three: addressing cross-border threats; improving economies of scale; and fostering the exchange and uptake of

best practices among MS. Secondly, Ms Meroni presented the results from the OPC, showing that administrative burden and the securement of co-financing are the two major barriers for the participation of low-GNI countries. She explained that Chafea's role allows to act upon both elements, and that, to increase the participation from low-GNI countries, these barriers can be addressed by simplifying processes. For example, the introduction of an electronic system for grants application (2014), has significantly reduced the administrative burden. Ms Meroni also stressed the importance of developing an electronic tool to address the third limitation and improve the monitoring of programmes implementation, getting real-time data, to inform decisions for future spending.

Ms Meroni then looked into the allocation of the 3PHP budget up to 2016. So far, objectives 1 (on health promotion) and 3 (on health systems) have received the highest amount of funding, with 33% and 31% of the total budget spent, respectively. Looking at the different funding mechanisms (JA, procurement contracts, projects, operating grants, DGA, etc.) the majority of the budget was allocated to JA (30%), procurement contacts (27%) and projects (24%). Looking at budget allocation by thematic priority, Ms Meroni showed that the funding ranged significantly across the 23 thematic priorities. Finally, looking at funding of projects across organisations, by countries, she showed that four countries alone (Estonia, Italy, UK, and Netherlands) took over half of the total budget allocated to projects (52%).

Ms Meroni then addressed the importance of developing specific indicators for each project, to understand to what extent actions contribute to the achievement of different objectives in the 23 thematic areas. Finally, to address the challenges regarding the dissemination of results, Ms Meroni stressed the importance of reaching wider audiences, utilising different communication means, including web tools, events, publications, and articles in scientific journals.

1.3. Part II: National Perspectives on the Opportunities and Limitations of the Health Programme

1.3.1. National Focal Point France

Mr ROUFFET started his presentation by thanking for the choice of engaging MS in the discussion of the 3PHP. He introduced himself as a professional with varied experiences in the field of public health, which gave him a good overview of how the 3PHP is working from different perspectives. He stated that all of the objectives of the 3PHP are highly relevant and aligned with MS's priorities.

Mr Rouffet introduced the state of play, showing that the EU is currently funding strategies in the field of health through various programmes. The budget allocated to the different programmes is significantly different, with the budget for the 3PHP being significantly lower compared to other programmes, such as the ESIF, EFSI, SRSP or H2020. Mr Rouffet then described the adoption process: the Commission proposes projects with indicating budget, followed by an initial consultation of MS. Based on this feedback the Commission elaborates a draft of the annual work programme, which is then submitted to MS, before going to the Health Committee. Once approved, Chafea implements the programme. Mr Rouffet expressed the concern that, while the inclusion of MS in the process is positive, some of the recommendations made are not taken into consideration.

Mr Rouffet presented his SWOT Analysis. Among the Strengths of the 3PHP he highlighted the focus on the public health policies and on key and common challenges; the fact that it is a multi-annual framework, ensuring continuity in projects; the outline of strategic priorities; and, as the most important point, the fostering of synergies among MS (e.g. in

JA), creating strong EU working communities. The three Weaknesses he identified were the budget, which is not enough to achieve the objectives of the programme, as well as issues in the continuity of projects funded, and finally the balance of JA and projects. MS strongly prefer JA. Regarding the Opportunities of the 3PHP, Mr Rouffet expressed the big prospect that the programme gives start to collaborative projects fostering synergies between policy makers, to fund projects in underexplored areas, and to encourage the convergence of public health policies. Finally, among the Threats, Mr Rouffet expressed his concern on the change in nomination rules for JA, which increased the complication for MS. Another threat is the interface with other programmes, and he suggested to increase the collaboration with the other programmes. A final threat is the sharing of mandatory financing, which leaves less funding available for JA, projects, etc.

Mr Rouffet then spoke about JA, and their value in contributing to improve national policies. France uses JA to share best practices between MS that are facing same challenges. At the European level, the 3PHP really fosters communication and collaboration, leading to a strong health democracy. The European Reference Network is a good example where there is some funding available to work together on rare diseases. Mr Rouffet spoke very positively of the new strategy focused on implementation, and he encouraged this trend. He then recommended to increase synergies among different health programmes, and to focus more on health literacy, to increase the impact of the 3PHP on citizens. Mr Rouffet concluded by emphasising the importance of the 3PHP for MS public health policies, and recognised that both at national and EU levels it is a challenge to get significant funding for health policies. He therefore encouraged the MEPs to create synergies with other colleagues from other fields (e.g. finance, education, etc.). He highlighted that 2020 will be a real milestone, because all multiannual frameworks will end and will have to be renewed, giving the chance to increase funding.

1.3.2. National Focal Point UK

Ms COLLEN recounted that she has been NFP of the Public Health Programme since the beginning of the 2nd Health Programme, and she has therefore been able to see the evolution of the programme since 2008. She cited the Mid-term Evaluation description of the 3PHP as a “small programme, with a big EU added value”, as a very accurate depiction of the programme, where all projects funded had a significant impact. As an example, she spoke about the successful work done to respond to cross-border EU health threats, both by EMERGE and QUANDHIP JA, that looked into capacity building of laboratories across the EU to deal with emergency health threats and crisis management response, which were extremely effective with threats such as the Ebola and the Zika Virus pandemics.

Ms Collen highly valued the collaboration across countries that gave the opportunities to achieve results which would not be possible if addressed only nationally. Moreover, she emphasised the critical operating costs towards European civil societies working on health that the 3PHP provides. Ms Collen strongly supported the decision to move to the framework partnership approach covering three years, given the limited available budget. Ms Collen agreed with Mr Rouffet on the added value of the European Reference Network for rare diseases. She also agreed on the important and unique added value brought from JA, which really support national health policies with concrete actions across the field. Following-up on Ms Meroni's presentation, she highlighted that, although the administrative burden for MS is high, the use of electronic platforms significantly improved the administrative work, as they are paperless, they bring all documents together, and allow to share documents.

Ms Collen then focused on the challenges of the 3PHP, and on recommendations for future actions. She reported that despite improvements, the administration processes are still very complex, with matched funding creating a lot of confusion. In terms of demonstrating impact, Ms Collen strongly agreed on the need to move from sharing knowledge to implementation, through programmes such as JA. In order to do so, however, the 3PHP will require more significant funding, which entails making a strong case for more funding in the next budget cycle. Ms Collen concluded with the recommendation of integrating health policies in broader issues concerning the EU.

1.3.3. Questions and Answers

Mr PETERLE opened the floor for one question. Dr Madan THANGAVELU, from the European Ayurveda Association, expressed his impression that institutions focused too much on the administrative side of the limitations of the 3PHP, rather than addressing cross-border shared issues such as the demographic transition and ageing population, by encouraging different stakeholders in MS to share ideas to address the challenge. Ms COLLEN agreed on the relevance of the question and on the importance of sharing ideas on common challenges, but answered that the 3PHP is actually funding a number of programmes for chronic diseases and e-Health infrastructures to promote healthy ageing, while, at the same time, having mechanisms in place to get suggestions from MS. Mr ROUFFET added that it is important to remember that the 3PHP is a tool to reach common goals, such as addressing the issues of an ageing population. He emphasised that there are different programmes from different DGs, however, that can be utilised to achieve the same goal. He stressed the importance that all funding should go toward the same direction and towards common goals.

Mr Miklós GYÖRFFI, Parliamentary Research Administrator, asked about how health inequalities across MS, often due to differences in public health policies and actions, are addressed by the 3PHP, and if they are taken into account. Ms ATHANASSOUDIS answered confirming that the place where you are born and live deeply affect your life expectancy and you HLY, and explained that this is due to both health determinants (e.g. smoking, physical inactivity, etc.), as well as to wider health policies. Given its multi-dimensional nature, Ms Athanassoudis confirmed that health inequalities are currently being addressed by the 3PHP as a horizontal objective of the programme, as it is linked to both objectives 1 (regarding health promotion and prevention of disease) and 3 (regarding healthcare systems). Mr Rouffet added that there is an ongoing JA that is directly targeting health inequalities.

1.4. Part III: Success Stories of the Health Programme

1.4.1. SUNFRAIL

Ms BARBOLINI spoke on the success story from the SUNFRAIL project. Linking to the two questions about ageing population and equity, Ms Barbolini introduced the SUNFRAIL project, which addresses frailty, a multi-dimensional irreversible condition affecting ageing population that needs to be addressed in its early stages with preventive measures. In today's EU context, with an ageing population, and consequent increase in the prevalence of frailty, chronic diseases, multi-morbidities and polypharmacy, EU-wide actions are essential. Funded by the 3PHP, SUNFRAIL aims to design an innovative integrated model for the care of multi-morbidity and the prevention and management of frailty, defined within both biomedical and the psycho-social paradigms.

Ms Barbolini described the tool developed by SUNFRAIL, which has four objectives: to design a model to prevent and manage frailty; to validate this model to address citizen's perceptions and needs; to assess the potential for the adoption and replication of the model; and to promote the dissemination of results at regional, national and EU level.

Ms Barbolini highlighted the issue caused by older citizens' fear of losing their independence not accessing services until they get an irreversible disability. Therefore, SUNFRAIL aims to bridge this gap by increasing early identification and prevention. To prevent frailty, all opportunities of contacts need to be used, through the SUNFRAIL tool - a 9-question tool, reflecting all aspects of frailty (the biomedical, psychological, social, and economic) used across the primary and secondary health care, community and social care services.

Ms Barbolini has then presented the main findings and results. In all settings in which the SUNFRAIL tool has been used, there was a high proportion of alerts in populations with no signs of disability. A higher level of frailty was found among women, in the oldest population, as well as in populations with lower levels of education, and greater financial difficulties. Moreover, specialists' tests showed that the alerts were being confirmed by a diagnosis. According to Ms Barbolini, the biggest element of success was the recognition of the tool as a user-friendly, easy to use, multi-disciplinary and useful test, that promoted available preventive services, as well as the integration of services and resources. The tool has already been integrated with health, social and community services in Emilia-Romagna, and its adoption has now been requested in various countries across the EU. Finally, the SUNFRAIL tool is extremely useful for the stratification of the population based on risk. By dividing the population into individuals at low risk, individuals at moderate risk, and individuals at high risk of frailty, more than 80% of the population will fall within the low risk band. Therefore, the SUNFRAIL tool could be extremely useful to work at primary care and community level in order to prevent frailty and reduce the disability that this condition is causing.

1.4.2. EURORDIS – Rare Diseases Europe

Ms Bottarelli stated that she had to choose one of the many success stories from EURORDIS, and she decided to focus on the Operating Grant that has funded a considerable part of their core activities for years.

Ms Bottarelli started her presentation by explaining EURORDIS's position in the field of rare diseases. Patients with rare diseases, although geographically scattered and isolated, become a significant proportion of the EU population, when looked at across diseases and borders. EURORDIS is a non-profit alliance of over 600 rare disease patient organisations, that aims to find solutions to common problems (e.g. lack of cure, chronic diseases, etc.), representing all patients with rare diseases. Moreover, not only patients but also experts, resources and literature is scarce and scattered across the EU. This rarity calls for action because no one country alone can face the challenges posed by rare diseases.

Ms Bottarelli introduced EURORDIS as a patient organisation that works across 60 countries. She then focused on the Operating Grant (received since 2009), which was used to build the patient community, to raise awareness, and for capacity-building, provided stability to the NGO, and allowed EURORDIS to focus on other elements too. However, she expressed a strong sense of instability felt at the end of each financial year due to the timeline of decision-making processes regarding annual agreements.

Ms Bottarelli then presented a few of the success stories from EURORDIS, such as the establishment of the "Rare Disease Day", which includes 94 countries worldwide, and the

organisation of the EURORDIS Summer School, aimed at empowering patients and researchers by teaching advocacy skills. Ms Bottarelli described the Operating Grant as an “enabler” that helped EURORDIS to contribute to EU policies. Speaking also for other NGOs in the EU, she highlighted the importance of the Operating Grant for recurrent operations, to secure stability and ensure diversification.

Ms Bottarelli then outlined the current challenges of Operating Grants, suggesting that they should be taken into account for the future ones. These include the reduction of funds occurring in parallel to the increase in complexity of health policy environments; lack of clarity and limited transparency on the evaluation process, as well as the uncertainty caused by the timeline of the decision-making processes; late payments; and the exclusion of NGOs from political cooperative projects (e.g JA), which limits NGOs’ participation to political debates and have relevant decision-making capabilities. She concluded her presentation by reiterating the importance of Operating Grants, and the importance of the 3PHP in general. Referring to the Eurobarometer results, Ms Bottarelli stressed the high expectations of citizens to have more actions in the field of health, and the need to strengthen this even more.

1.4.3. Questions and Answers

Mr PETERLE invited MEP Karin KADENBACH to speak. After thanking for the material and organisation of the workshop, she noted that health is not only a question of the health committee, but of all committees. She asked the NFP representatives why there is not more investment on prevention, as it is the most cost-effective measure to promote health. Adding on Ms Kadenbach’s question, Dr Thangavelu stated that going towards more democratised and prevention-focused health agenda, there will be a growing conflict between what policy makers and citizens see as added value.

Mr Zoltán MASSAY-KOSUBEK, policy manager of the European Public Health Alliance, stated that there is a gap between institutions and citizens’ expectations in terms of the addition of value to the Programme. He characterized the current political context as one where there is pressure to reduce EU action, and the 3PHP might be affected by this new trend. Ms Athanassoudis commented that DG SANTE does not hide that the 3PHP has a small budget, which is very hard to manage. For the future, Ms Athanassoudis said that a lot will depend also on how much all MS will spend on all EU programmes, and not only on the Public Health Programme. Mr Rouffet added that there is the risk that in the future health will not remain among the priorities of the EU. He referred to the White Paper published by the president of the EC, where there is one scenario that has less budget for public health policy. Mr Rouffet emphasised the need to advocate for the Health Programme to be better recognised and make sure that health remains high on the agenda of policy makers.

1.5. Closing Remarks

Mr Peterle MEP concluded the session by recollecting that this is his third mandate and in 2004, the discussions were very different. He stated the importance of the 3PHP in the political picture of the EU, and reflected on the frequent use throughout the workshop of words such as “collaboration”, “synergies”, and “partnership”, which reflect a change in working structures. Mr Peterle also highlighted the urge to promote the 3PHP more, to ensure for it a higher status among MEPs, and to advocate for higher funding in the next cycle. He was pleased to witness the “osmosis between EU and MS”, and he believes that there are many reasons to ensure a higher status in the hierarchy of EU priorities, essential to prepare for the new cycle starting in 2020.

ANNEX 1: PROGRAMME

Co-Chairs: Ms Soledad CABEZÓN RUIZ (MEP) and Mr Alojz PETERLE (MEP)

The workshop aims to inform the Members of the ENVI Committee and all participants on the limits and potentials of the Third Public Health Programme (2014-2020). The workshop will be divided into three parts: the first part of the workshop will focus on the limitations of the programme with two presentations critically looking into the Third Health Programme's areas of improvement, and issues around accessibility to the programme. The second part will look at specific national contexts; and the last part of the workshop will cover success stories of the programme.

AGENDA

10:00 – 10:10 Opening and welcome by the Chairs Ms Soledad CABEZON RUIZ (MEP) and Mr Alojz PETERLE (MEP)

Part 1 – Institutional Panel Focused on Lessons Learnt from the Health Programme

10:10 – 10:20 **Presentation by a representative of DG-SANTE**

Ms Irene ATHANASSOUDIS
Policy Officer, DG SANTE

The presentation will touch upon policy aspect of the Public Health Programme, e.g. results of Mid-term evaluation, new approach focused on implementation instead of the creation of best practices

10:20 – 10:30 **Presentation by a representative of Chafea**

Donata MERONI

Head of Health and Food Safety Unit, Chafea

The presentation will focus on some limits of the Health Programme, lessons learnt and improvements to simplify procedures in relation to the Programme: e.g. new electronic tool to manage grants, Operating Grants framework partnership agreement, database of projects, NFP network, dissemination.

10:30 – 10:45 **Questions and Answers Session**

Part 2 – National Perspective on the Opportunities and Limitations of the Health Programme

10:45 – 10:55 **Presentation by a representative of a National Focal Point**

Jean-Baptiste ROUFFET, NFP France

Conseiller Affaires Européennes, Mission des Affaires Internationales et Européennes

Direction Générale de la Santé, Ministère des solidarités et de la Santé

Mr Rouffet is the French representative to the Health Programme Committee and will talk both about the elaboration of the programme and its implementation.

10:55 – 11:05 Presentation by a representative of a National Focal Point
Sarah COLLEN, NFP UK
Senior Policy Manager
NHS European Office

11:05 – 11:20 Questions & Answers Sessions

Part 3 - Success Stories of the Health Programme

11:20 – 11:30 Presentation from SUNFRAIL
Mirca Barbolini
Project Co-ordinator
Emilia Romagna Region ASSR

11:30 – 11:40 Presentation from EURORDIS-Rare Diseases Europe
Valentina Bottarelli,
Public Affairs Director
Head of European and International Advocacy, EURORDIS

11:40 – 11.55 Questions & Answers Sessions

11:55 – 12:00 Closing remarks by the Chairs

ANNEX 2: SHORT BIOGRAPHIES OF EXPERTS

Ms Irene ATHANASSOUDIS



Irene Athanassoudis joined the Commission in 1997 and since 2003 she has worked for Directorate General for Health and Food Safety as policy officer. She has closely followed the negotiations with Council and European Parliament for the adoption of the 3rd Health Programme 2014-2020. She is the responsible officer for the evaluations of the Health Programmes.

Ms Donata MERONI



Donata Meroni is Head of the Health and Food Safety Unit in the Consumers, Health, Agriculture and Food Executive Agency of the European Commission since 1 September 2017. Her Unit implements the annual plans of the Health Programme and the Better Training for Safer Food Initiative in close cooperation with DG SANTE. She has been with the Commission since 2002, when she joined DG SANCO to work at the Food and Veterinary Office in Ireland as a plant health inspector.

In 2006, she moved to Public Health Directorate in Luxembourg, working as deputy head of the 'Health Programme' Unit dealing with Health Programme coordination and health communication issues. She managed the implementation of the second and the negotiation of the third Health Programme and was in charge of the coordination with the Executive Agency. In the health communication portfolio, she managed the 'Ex-smokers are unstoppable' anti-tobacco campaign, the five editions of the EU Health Prize for journalists, the Public Health website, the Health Portal and the Health EU newsletter.

From 2013 to 2017 she has worked as deputy head of 'Country Knowledge and Scientific Committees' Unit managing the Secretariat of the Commission Scientific Committees (SCCS and SCHEER), dealing with EMF dossier and with Health information issues.

Donata is a chartered agronomist with a Master's degree in Agricultural Sciences from Milan University and she worked in Italy for more than 13 years in both the private and public sectors as a nursery chief technician, ecology expert and agriculture officer.

Mr Jean-Baptiste ROUFFET



Jean-Baptiste Rouffet is currently Policy Advisor on European Affairs at the Directorate General for Health of the Ministry for Health in France. He has also been mandated by Minister Agnès Buzyn to coordinate the interministerial taskforce on the European Medicines' Agency relocation and provides some teachings on European Affairs at the French School of Public Health (Rennes). Occasionally, he does some consultancy work on European Affairs.

Jean-Baptiste has led France to coordinate the European Joint Action on antimicrobial resistance and healthcare associated infections that

was launched in Paris on 13th September 2017. He contributed to promote an inclusive approach on AMR involving key stakeholders in this European project such as WHO Euro, OIE, OECD, FAO, ECDC, industry and health professionals. He also led France to coordinate the Joint Action on Vaccination and is also involved in the preparatory works of this project.

Over the years, Jean-Baptiste has been active on health determinants (Tobacco, Nutrition, Alcohol and Physical activity) voicing France's evidence-based policies. He has also contributed to the French active involvement at international level on International Health security. Jean-Baptiste has contributed to shape the European public health agenda, representing France in various settings (i.e Health programme Committee, Health Forum Gastein, Chief Medical Officers or Global Health security initiative).

Previously, he worked at the European Union of Medical specialists coordinating the work of medical specialists on medical training and engaging with key institutional and non-governmental stakeholders. In this respect, Jean-Baptiste supported the development of the Council for European medical specialist Assessment (CESMA) as well as the European Accreditation Council for Continuing Medical Education (EACCME).

He has a Master's degree in International and European Law from the Institute of Political Studies of Lille.

Ms Sarah COLLEN

Sarah Collen has 17 years of experience working in Brussels on EU public affairs. She joined the NHS European Office in 2013 as Senior Policy Manager. On top of representing the NHS in negotiations on European legislation that could have an impact on the service, she has played an active role in promoting EU funding opportunities to the NHS, including EU research and innovation funding (from Horizon 2020) and funding to support public health initiatives (EU Health Programme). In terms of EU legislation, she has most recently worked on the Medical Devices Regulations and also the EU General Data Protection Regulation. She has been the UK's National Focal Point for the EU Health Programme since 2014. She previously worked in the European Parliament and has also directed a Brussels based non-governmental organisation working in the field of development and human rights.

Ms Mirca BARBOLINI

Mirca Barbolini - Public Health and European Commission Senior Expert, with 25 years of work experience in the design, implementation and evaluation of European and International programmes/projects on Health, Social and Governance Issues.

She is currently collaborating with the Public Health Agency of the Emilia Romagna Region, coordinating the Sunfrail project and providing technical assistance to the EC Joint Action on Frailty-Advantage.

She has worked also with other Italian Region on the design and implementation of regional health and social services, and with Foromez PA and the Italian Ministry of Health, providing technical assistance and training on Public Health Services planning, monitoring and evaluation.

For the European Commission, she has collaborated as Health Expert for strategic planning in Primary Health Care, Reproductive Health and Hospital sector development, and as Expert Evaluator of Project Proposals in the field of Public Health, Chronic/Non-Communicable Diseases, Sexual Reproductive Health Rights and Governance.

Ms Valentina BOTTARELLI

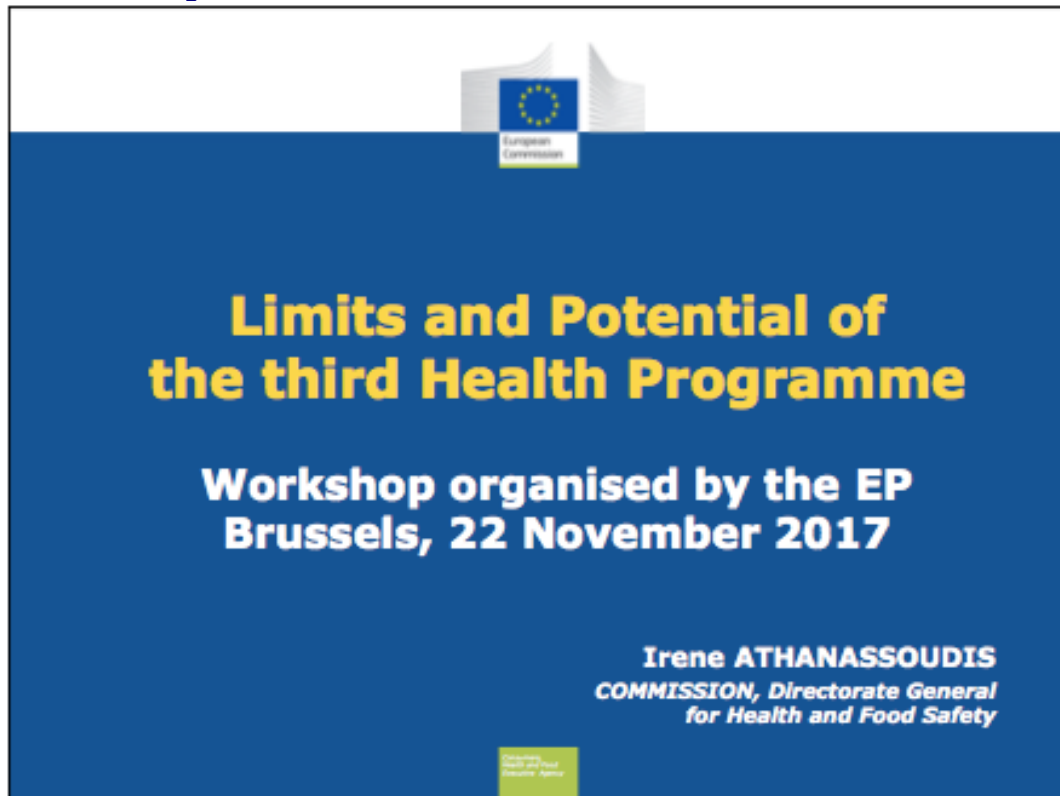
Valentina Bottarelli has been working with EURORDIS, the European Organisation for Rare Diseases, since 2007. As Director for Public Affairs and Head the International and European Advocacy Team, she helps raise awareness on rare diseases in the EU policy agenda by providing policy analysis and strategic advice on EU policies as well as funding opportunities from EU public institutions. She is also in charge of coordinating, on behalf of EURORDIS, activities aimed at fostering the development of National Plans on Rare Diseases in EU countries. She supervises EURORDIS contribution in CHAFEA-supported projects, including RD-ACTION, the Joint Action for Rare Diseases.

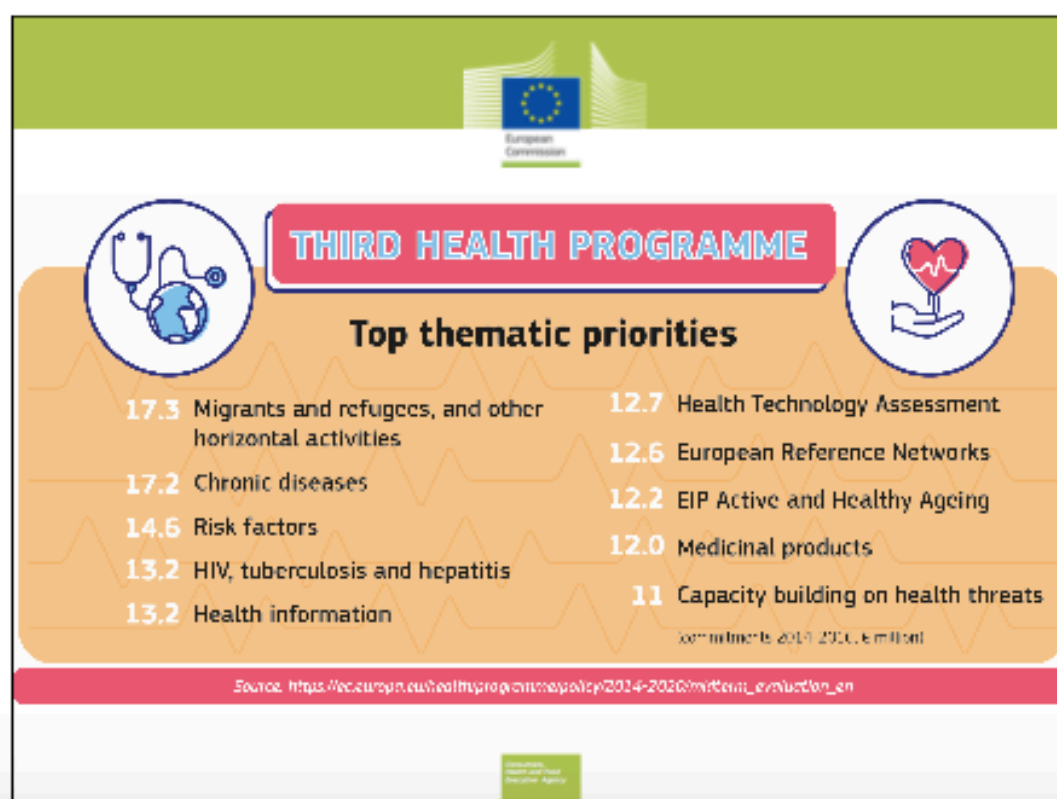
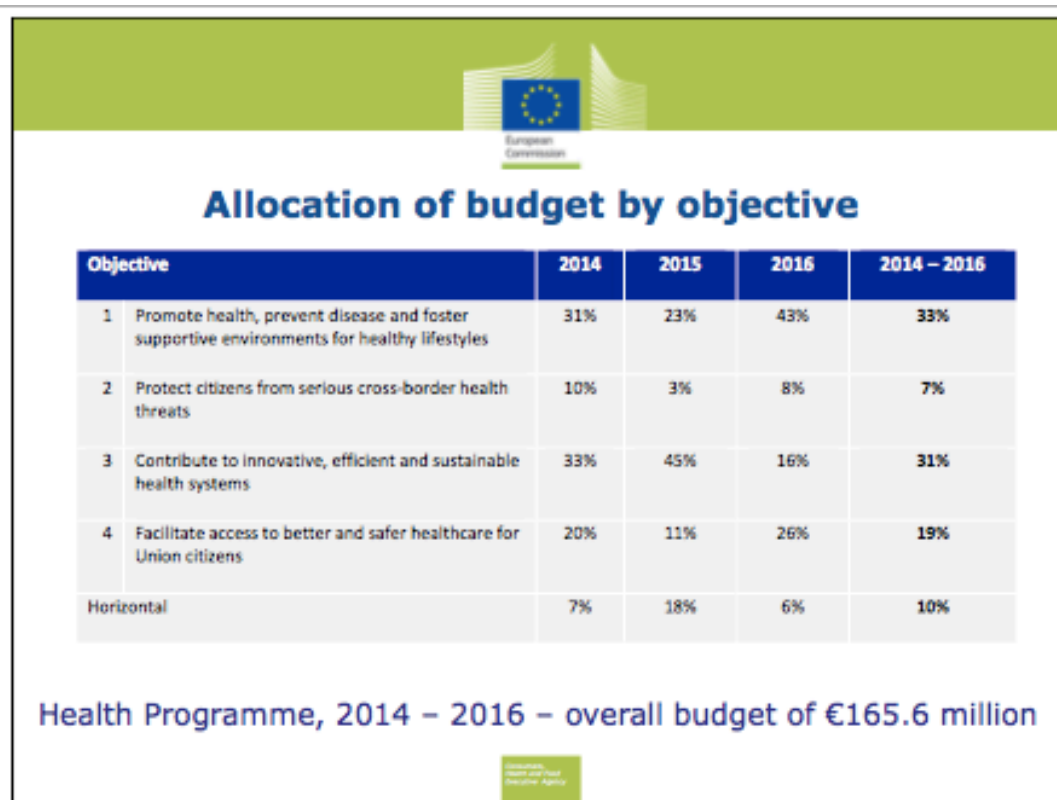
Valentina has extensive experience in the area of EU policies and programmes. As well as managing European funded projects, she has been working for six years as senior consultant in European public affairs at a FleishmanHillard in Brussels. She has also worked at the European Commission, Directorate External Affairs.

Valentina has a honour degree in Political Sciences from the LUISS (Rome), where she specialised in EU law, and a MA in European Politics and Administration from the College of Europe, Bruges. An Italian national, she speaks Italian, French, English and Spanish.

ANNEX 3: PRESENTATIONS

Presentation by Ms Irene ATHANASSOUDIS







European Commission

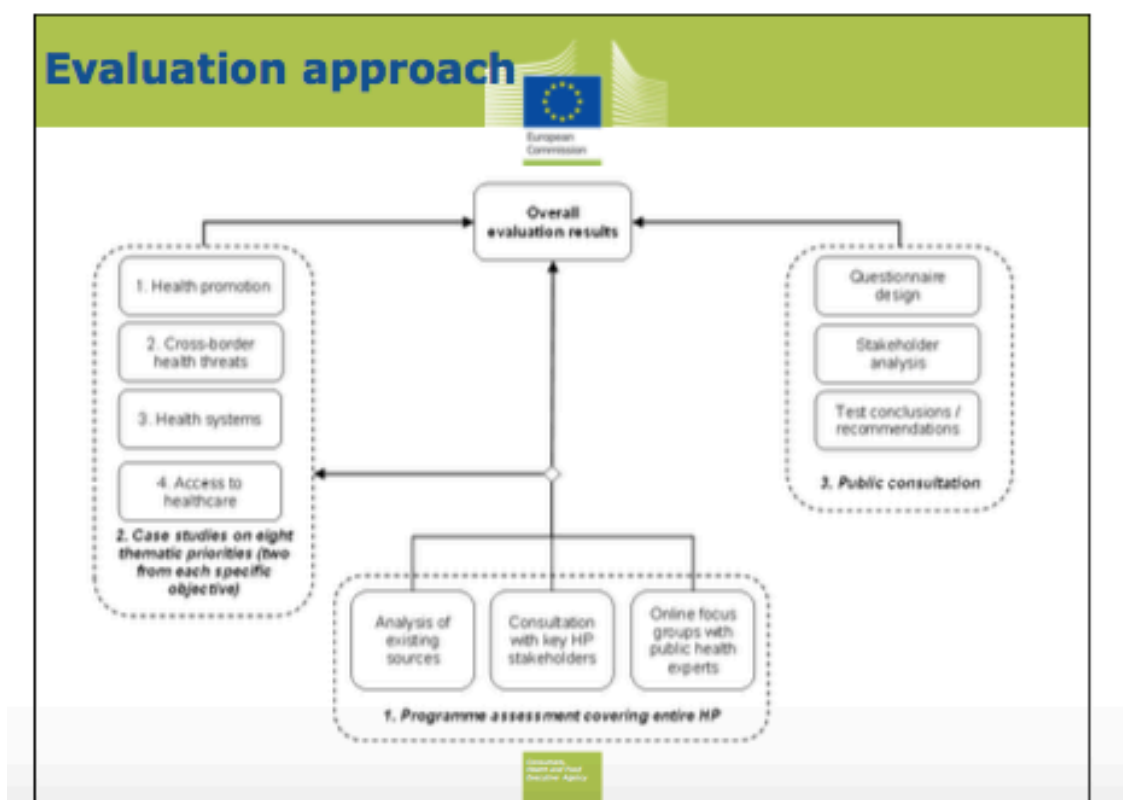
Mid-term evaluation

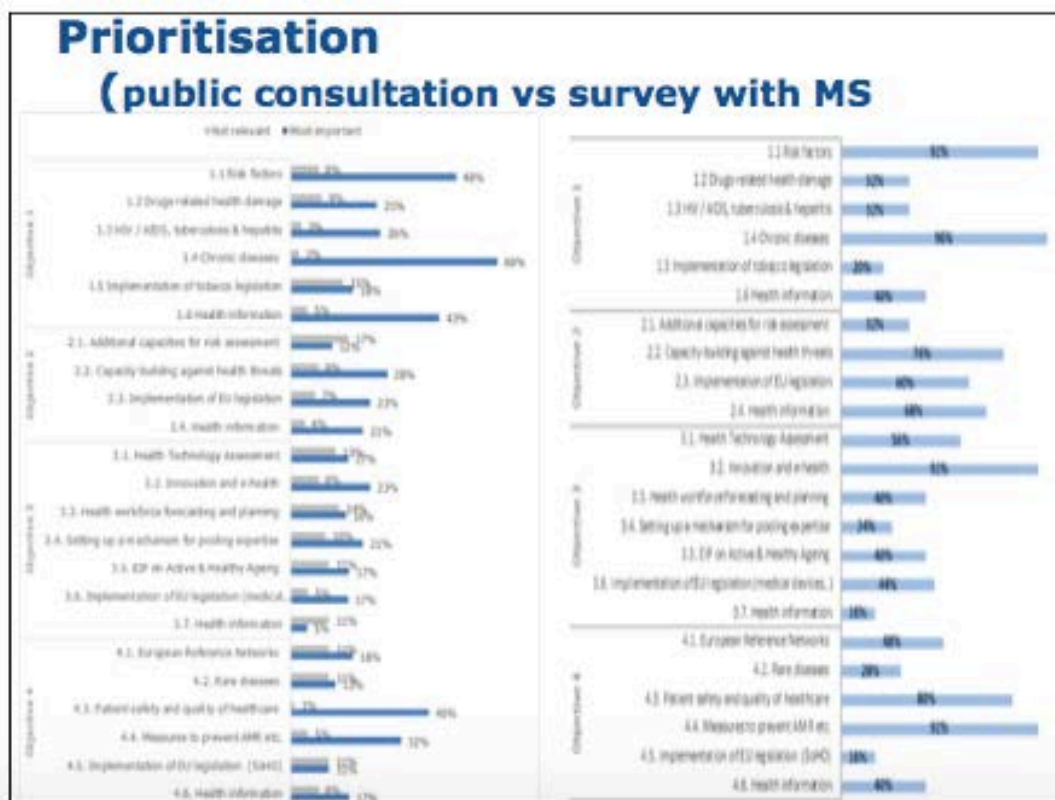
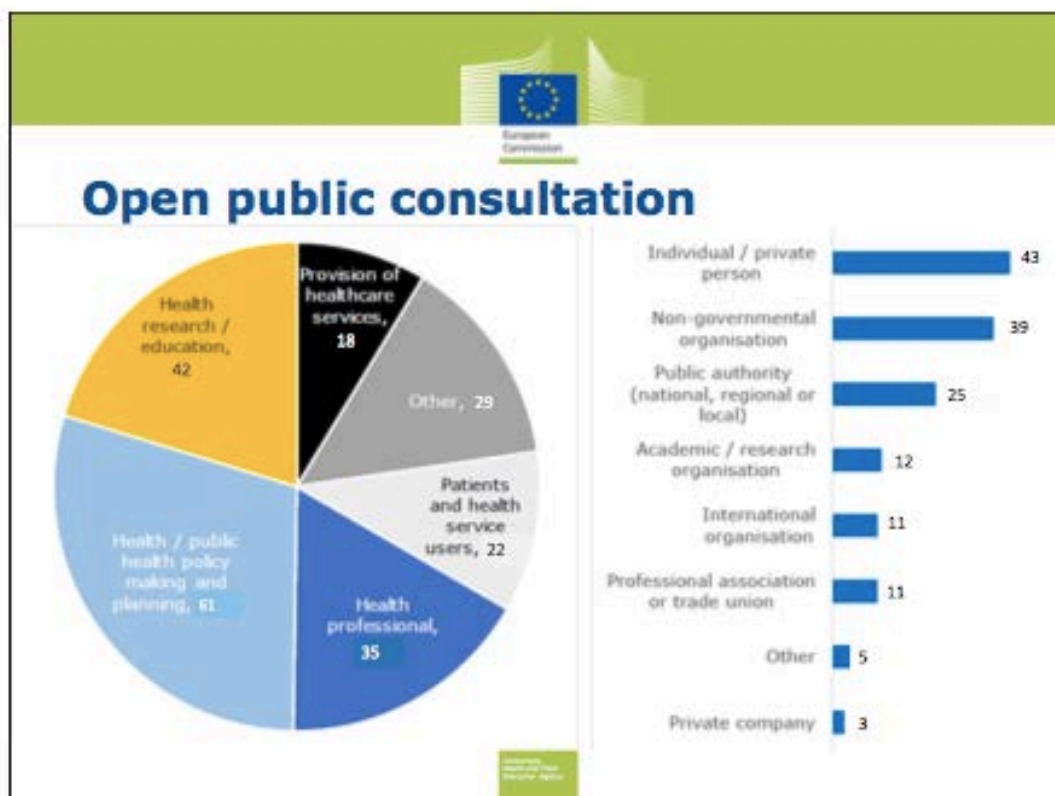
- **legal obligation** (Article 13 of Regulation (EU) No 282/2014)
- **external independent study** (05/2016- 06/2017)
- **Commission report to EP and Council on the results of the mid-term evaluation of the 3rd Health Programme** (11/10/2017)
https://ec.europa.eu/health/programme/policy/2014-2020/midterm_evaluation_en

✓ **Results from the ex-post evaluation of 2nd Health Programme:**
Commission report to EP and Council (10/05/2016)
https://ec.europa.eu/health/programme/policy/2008-2013/evaluation_en



European Commission







Overall conclusions

- Relevance to health needs
- Objectives set are clear, explicit and specific
- Programme management has become increasingly effective
- Efficiency is being improved
- The actions funded are of strong EU added value
- Simplification measures have been taken

European
Health and Food
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Lessons learnt (2)



Major achievements

- Establishing 24 European Reference Networks on rare diseases;
- Supporting Member States to increase their capacity-building to respond to outbreaks (e.g. Ebola and Zika viruses);
- Contributing to the EU's migration policy by supporting Member States to respond to the health needs of high influx of migrants and refugees; and training health professionals and other front-line staff.

European
Health and Food
Executive Agency

Lessons learnt (5)



Major achievements

Transfer of knowledge and implementation of best practices, mainly under the 1st objective for promotion of health and prevention of diseases

- alcohol harm reduction,
- Chronic diseases
- cancer screening,
- HIV/AIDS and TB prevention

European
Health and Food
Security Agency



Major achievements

Uptake of innovation in public health intervention and prevention strategies

- support for EU health legislation on medicinal products and medical devices,
- eHealth Network activities and Health Technology Assessment

European
Health and Food
Security Agency



Major achievements

The State of Health in the EU

- 28 Country-Health Profiles alongside their Companion Report
- prepared by the OECD and the European Observatory on Health Systems and Policies, in cooperation with the Commission,
- whereas the Companion Report is the Commission's own analysis of cross-cutting topics and their EU value added.

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Executive Agency



Lessons learnt (1)

Maintain focus on thematic areas of strong EU added value

- No need for changing the structure of thematic priorities in the immediate term given their importance for monitoring spend over time.
- In the longer term beyond 2020, consider further streamlining any thematic priorities to avoid any potential overlap or ambiguities but also to remove apparent redundancies

European
Health and Food
Executive Agency




Lessons learnt (2)


Strengthen and build links between the HP and the wider Commission and EU policy agenda to maximise visibility and impact

- Links to Sustainable Development Goals
 - ❑ *"Ensure healthy lives and promote well-being for all at all ages"*
- Development of synergies with the Commission's main priorities and other programmes
 - ❑ *Ensure that the investments through other funds and Programmes respect the agreed EU health policies*







Other funds and Programmes



European Fund Strategic Investment (EFSI)



European Structural Investment Funds (ESIF)





Structural Reform Support Programme (SRSP)

- 17 projects in Health in 9 Member States for an overall of 1,072 billion euros
- 437 million for health infrastructure and services, and
- 635 million for medical research.
- EFSI 2.0 (expected by end of the year)

- European Social Fund of 4.2 billion euros
- Over 9 billion euros for health-related investments
- Differences across the Member States in terms of scope and impact.

- Helping EU countries to design and implement structural reforms, apply EU law and use EU funds
- Support inter alia to reforms in areas related to labour market, health and social services
- 3 million euros under SRSP and an additional 3 million euros under other financing modes
- 25 projects related to health will receive support for technical assistance (1st call 2017)






Lessons learnt (3)

Spell out how actions targeting health promotion and health systems should generate EU added value

- *In the immediate term:* define the mechanisms by which best practices should be taken up in practical terms and reasonable timescales for doing so (either in general or with regard to specific funding calls).
- This information should then be shared with key stakeholders such as potential applicants and NFPs.



Concretely



Steering Group on Promotion and Prevention Objectives:

- Select interventions for implementation, contributing to Sustainable Development Goal #3
- Fill the gaps identified in the 'State of Health'
- Select interventions from Joint Actions and projects, explore national implementation using EU funds






From identification of best practices to their implementation in national policies

- **Criteria for selection of interventions agreed with Member States**
https://ec.europa.eu/health/sites/health/files/mental_health/docs/compass_bestpracticescriteria_en.pdf
- First set of best practices selected for implementation at national level
- National priorities and strategies guide the selection of best practices



Thank you!

Presentation by Ms Donata MERONI



**European Parliament
workshop: Limits and Potential
of the Public Health Programme**

**22 November 2017
Brussels**

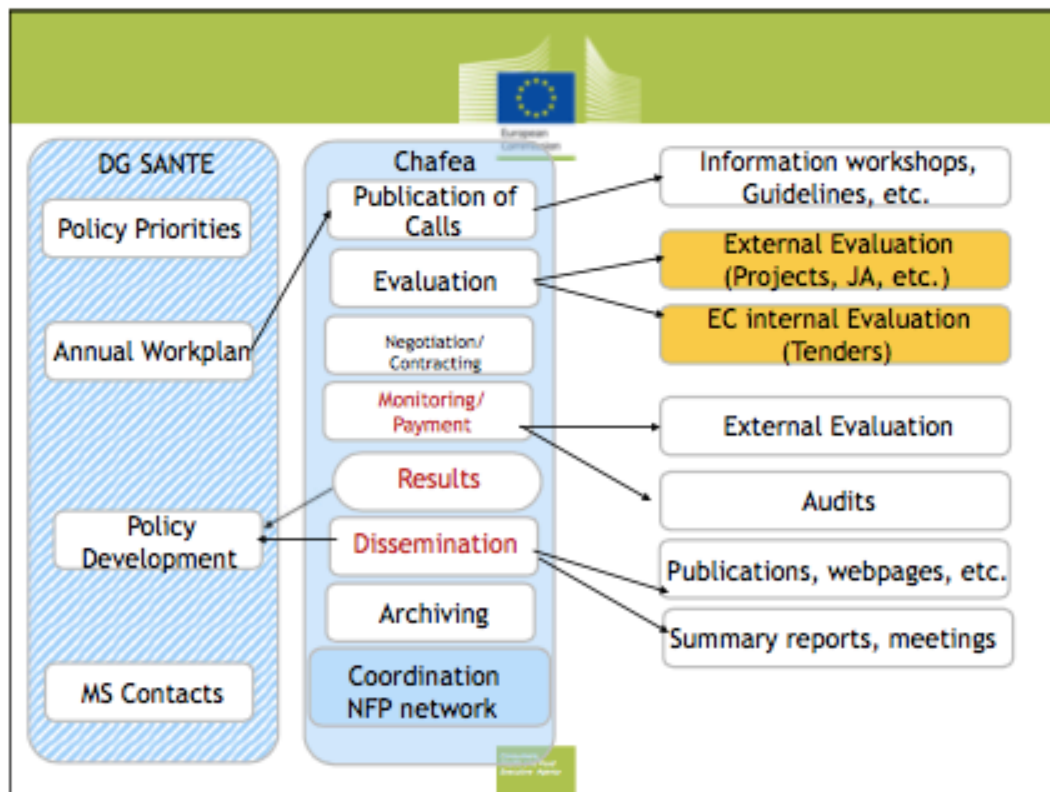
Donata Meroni
*Head of the Health & Food Safety Unit
Consumers, Health, Agriculture and Food Executive Agency*



Chafea
**Consumers, Health, Agriculture
and Food Executive Agency**

**Helping the Health Programme
to run better**





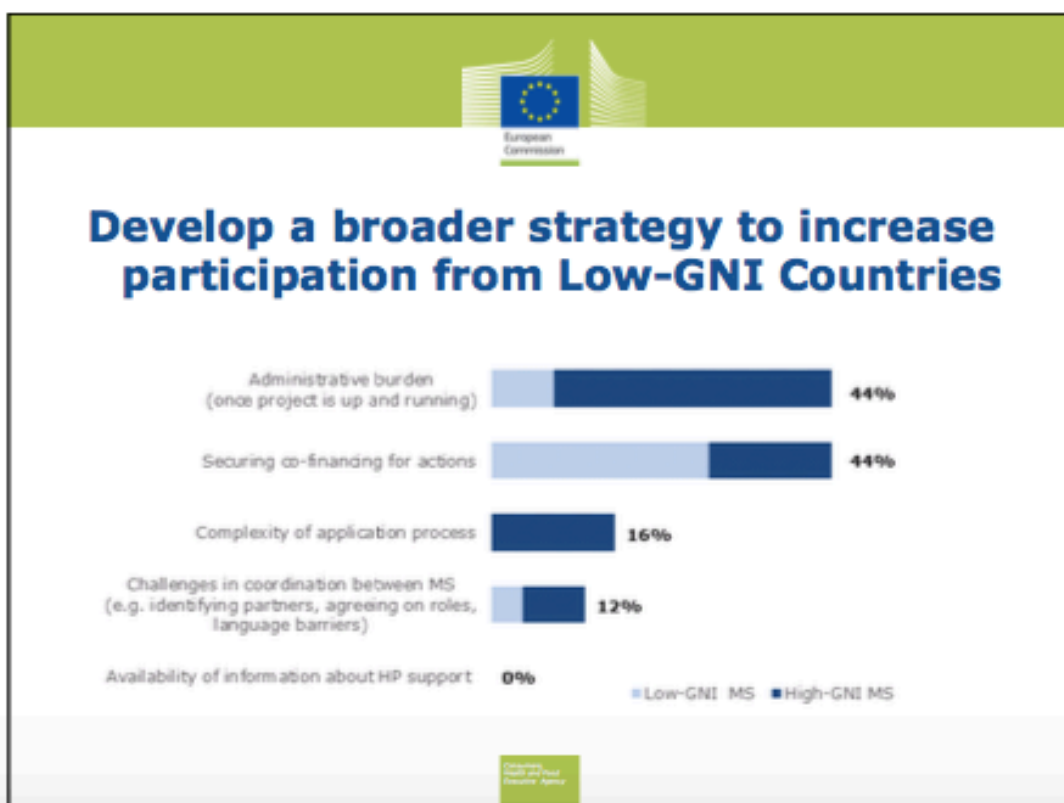
The graphic shows three stylized hands in purple, blue, and green, each holding a document, symbolizing collaboration and shared action.

The Mid-term evaluation recommends 5 areas of action for Chafea




Refine the EU added value and fully integrate it into the application process

- Explain to applicants and evaluation panels what each criteria mean
- Simplify and re-group the seven criteria in just 3

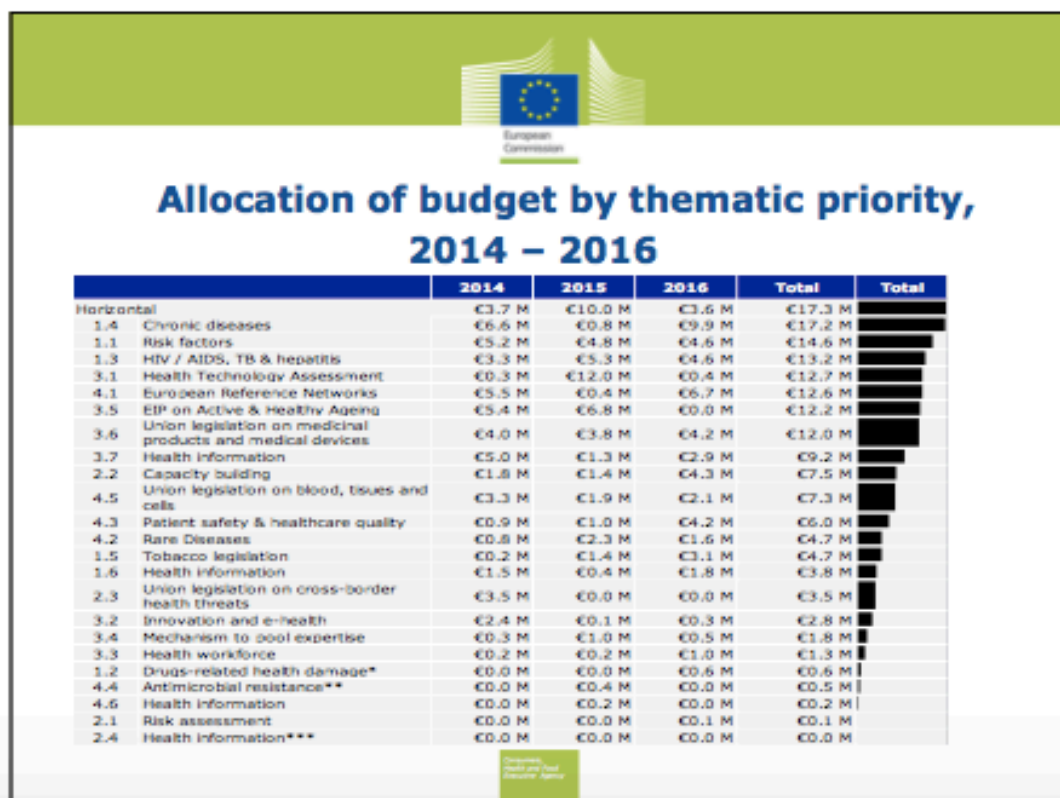
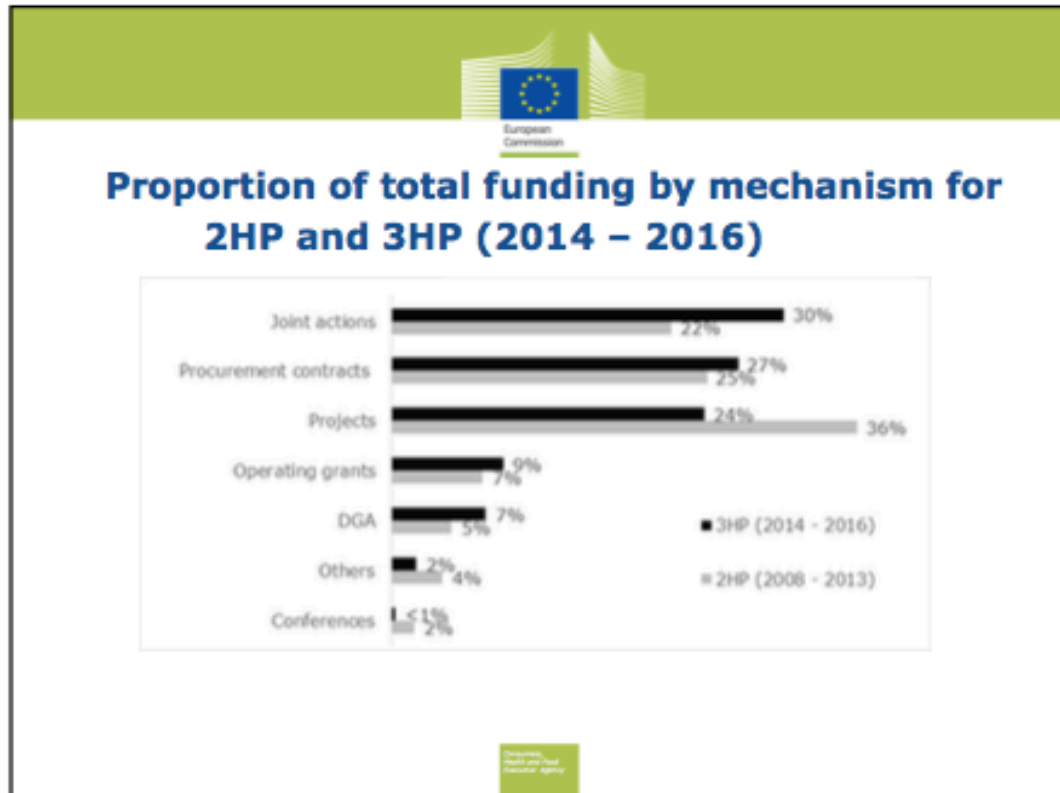






Allocation of budget by Health Programme objective, 2014 - 2016

Objective	2014	2015	2016	2014 – 2016
1 Promote health, prevent disease and foster supportive environments for healthy lifestyles	31%	23%	43%	33%
2 Protect citizens from serious cross-border health threats	10%	3%	8%	7%
3 Contribute to innovative, efficient and sustainable health systems	33%	45%	16%	31%
4 Facilitate access to better and safer healthcare for Union citizens	20%	11%	26%	19%
Horizontal	7%	18%	6%	10%

European Commission
Directorate-General for Health and Food Safety




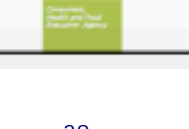



European Commission

Implement and use monitoring indicators

To what extent actions contribute to the achievement of different objectives in the 23 thematic areas




European Commission



Communicate about HP with core stakeholders and wider audience

Web tools (data base, sites, newsletters, webinars, tutorials)

Events (cluster meetings, conferences, etc.)

Publications

Articles in scientific journals



European Commission
European Health and Food Regulatory Agency



To know more about Chafea

<http://ec.europa.eu/eahc/about/about.html>
Website

<http://ec.europa.eu/chafea/health/index.html>
Project Data base

https://webgate.ec.europa.eu/chafea_pdb/health/projects/

Thanks

European Commission
European Health and Food Regulatory Agency

Presentation by Mr Jean-Baptiste ROUFFET



LIBERTÉ • ÉGALITÉ • FRATERNITÉ
RÉPUBLIQUE FRANÇAISE
MINISTÈRE
DES SOLIDARITÉS
ET DE LA SANTÉ

A perspective on the Health Programme:

Mr Jean-Baptiste Rouffet
Policy Advisor on European Affairs– Ministry of Health – France

Who am I?

- ▶ **Present occupations:**
 - ▶ Policy Advisor on European Affairs at Ministry of Health
 - ▶ National Focal Point
 - ▶ French representative to Health programme
 - ▶ Member of the French coordination teams of EU-JAMRAI and EU-JAV
 - ▶ Consultancy on European affairs
 - ▶ Teachings on European affairs at French School of Public Health (EHESP) and French School of Administration (ENA)
- ▶ **Past occupations:**
 - ▶ Coordinator at the UEMS: active role in CESMA, PGT, Common Training Frameworks, European Accreditation



Field of expertise:

- European affairs
- International organisations
- Public Health policies
- Accreditation
- Project Management
- Campaigns



French view on the Health programme in the EU – 25th November 2017 – European Parliament

Outline

- ▶ The state of play
- ▶ SWOT Analysis
- ▶ Proposals
- ▶ conclusions



STATE OF PLAY - Existing fundings in health

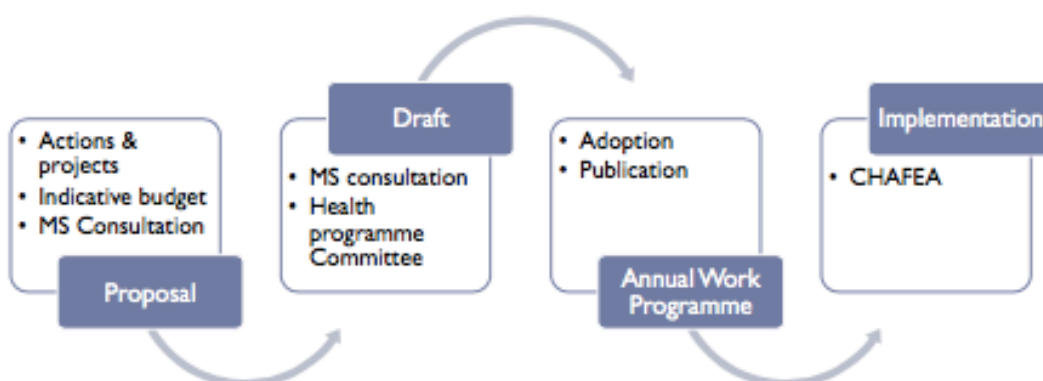


STATE OF PLAY – HP objectives

- ▶ Underpins EU health policy coordination in order to complement, support and add value to the national policies of Member States.
- ▶ Fully respects MS autonomy to define their own health policies and to organise and deliver health services and medical care within their borders
- ▶ Supports implementation of EU health legislation
- ▶ 4 objectives:
 - ▶ promote health, prevent diseases and foster supportive environments for healthy lifestyles,
 - ▶ protect Union citizens from serious cross-border health threats,
 - ▶ contribute to innovative, efficient and sustainable health systems, and
 - ▶ facilitate access to better and safer healthcare for Union citizens.



STATE OF PLAY – adoption process



HEALTH PROGRAMME SWOT ANALYSIS

Strength

- ▶ Focused on public health policies
- ▶ Addresses key and common challenges
- ▶ Multi annual framework
- ▶ Strategic priorities
- ▶ Useful to foster synergies among member states
- ▶ Create EU working communities

Weaknesses

- ▶ Underbudgetted (+/- 60m€/year)
- ▶ Continuity of projects funded
- ▶ Balance Joint Action/call for projects



HEALTH PROGRAMME SWOT ANALYSIS

Opportunities

- ▶ Collaborative projects foster synergies between policy makers (i.e. JA)
- ▶ Funding for underexplored areas
- ▶ Convergence of Public Health policies

Threats

- ▶ Change in nomination rules for Joint Actions
- ▶ Interface with other programmes (H2020, ...)
- ▶ Share of mandatory financing (EDQM, ...) vs JA & projects



ADDED VALUE OF HP FOR FRANCE

- ▶ **France involved in several Joint Actions**
 - ▶ As contributor and WP Leader
 - ▶ JA on Management of Frailty (2016-2019)
 - ▶ JA on Rare Diseases (2015-2018)
 - ▶ JA on Rare Cancer (2016-2019)
 - ▶ JA Health Information (2018-2021)
 - ▶ Or coordinator
 - ▶ JA on Nutrition and Physical Activity (2015- 2018)
 - ▶ JA on Antimicrobial resistance (2017-2020)
 - ▶ JA on Vaccination (2018-2021)
- ▶ **JAs contribute to improving national policies**
 - ▶ Exchange of best practice
 - ▶ Collaborative approach
 - ▶ Common recommendation



THE ADDED VALUE OF THE HEALTH PROGRAMME FOR EUROPE

- ▶ **Health programme fosters synergies across policy-makers and stakeholders (health democracy)**
- ▶ **Health programme supports the EU's objectives/ convergence (i.e. ERN)**
- ▶ **Recent-years' focus on implementation is ++**
- ▶ **Impact on citizen's could be further enhanced through better synergy of EU fundings / health literacy focus**

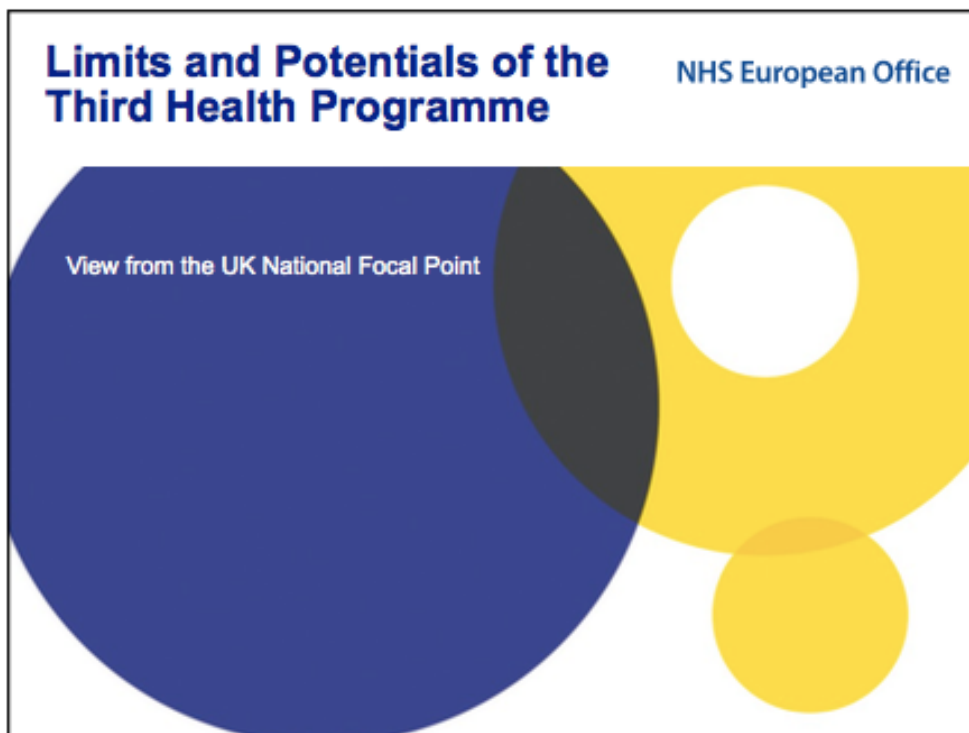


Conclusion

- ▶ Health programme supports MS Public Health policies
- ▶ MS and Commission share common challenge of to have health in all policies (ex :AMR, climate change, etc.)
- ▶ Health in all policies should be promoted through funding mechanism
- ▶ 2020 is a major milestone as most European multiannual financial framework will have to be renewed
- ▶ Increasing HP budget to impact on EU citizens



Presentation by Sarah COLLEN



NHS European Office

Health security, preparedness and crisis management

Particular EU value added: protecting UK citizens from serious cross-border health threats.

Supporting collaboration with colleagues across the EU, allowing access to resources which would have been inaccessible at national level.

QUANDHIP & EMERGE have supported an integrated laboratory network for detecting highly infectious pathogens.



The screenshot shows the EMERGE website, which is dedicated to 'Efficient response to highly dangerous and emerging pathogens at EU level'. It features a navigation bar with links to Home, Contact, Impact, Strategy, Data Policy, and Publications. The main content area includes an 'About us' section, a list of 'Partners' (including the Robert Koch Institute), and a 'Pathogens' section. The website describes the EMERGE project as a collaborative effort to develop and implement a coordinated response to high-risk pathogens, aiming to protect public health across Europe.

NHS European Office

European Chemical Emergency Network (ECHEMNET):

“Taken together the Health Programme has provided us with a robust framework to help support applied collaborative research and development in the area of health protection and chemical hazards” Rob Orford, Public Health England



The screenshot shows the ECHEMNET website, which is the European Chemical Emergency Network. It features a navigation bar with links to Home, Contact, Impact, Strategy, Data Policy, and Publications. The main content area includes an 'About us' section, a list of 'Partners' (including the Robert Koch Institute), and a 'Pathogens' section. The website describes the ECHEMNET project as a collaborative effort to develop and implement a coordinated response to high-risk chemical emergencies, aiming to protect public health across Europe.

NHS European Office

European civil society working on health



FUNDING UNDER THE 3RD HEALTH PROGRAMME 2014-2020

CALL FOR PROPOSALS

Operating Grants


Operating grants are one funding instrument under the third EU Health Programme 2014-2020. The Health Programme is about fostering health in Europe by encouraging cooperation between Member States to improve the health policies that benefit their citizens. The programme aims to support and complement Member States health initiatives.

The Programme is translated into annual work programmes defining actions in priority areas set in the Programme Regulation (EU) No282/2014.


On this basis the Consumer, Health and Food Executive Agency organises every year a call for proposals. Only proposals that directly correspond to the topic and description as set out in the annual work programme will be considered for funding. Proposals that only address the thematic area but do not match the specific description of a given action will not be considered for funding.

NHS European Office


Contribution to ERNs




> 300
HOSPITALS



> 900
HEALTHCARE UNITS



THOUSANDS OF
PATIENTS HELPED
BY 2020



EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

Share. Care. Cure.

European Reference Networks

NHS European Office

Joint Actions

Unique instrument for sharing experience/knowledge across member states



NHS European Office

New IT infrastructure



Challenges

- **Administration processes**
- **Demonstrating impact : from knowledge sharing to implementation, but implementation requires significant funding**
- **Profile and budget during the next FP – making the case for funding**

Presentation by Mirca BARBOLINI



**limits and potential
of the Public Health Programme**

SUCCESS STORIES OF THE HEALTH PROGRAMME

SUNFRAIL

Emilia-Romagna Region
Mirca Barbolini & Team

at the European Parliament, Brussels, 22nd November 2017

 Reference Sites Network for Prevention and
Care of Frailty and Chronic Conditions in
community dwelling persons of EU Countries

 Co-funded by
the Health Programme
of the European Union

The SUNFRAIL Project has
received funding from the
European Union's Health
Programme 2014-2020



project ID

EIP on AHA context
the network of the **Italian Reference Sites**

3rd EU Health Programme - WP 2014

To improve the **identification, prevention and management**
of **frailty** and care of **multimorbidity** in **community dwelling**
persons (over 65) of EU countries

Italian context
Ministry of Health, **Progetto Mattone Internazionale**

  Co-funded by
the Health Programme
of the European Union

the partnership

partner	organisation	acronym
RS LP1	Regione Emilia-Romagna – Agenzia Sanitaria e Sociale Regionale – I	RER-ASSR
	Aster - Società Consortile Per Azioni – I	ASTER
RS PP2	Regione Piemonte – I	RHAP
RS PP3	Regione Liguria – I	LIGURIA
	Galliera Hospital	Affiliated
RS PP4	Azienda Ospedaliera Universitaria Federico II, R. Campania – I	
RS PP5	Centre Hospitalier Universitaire De Toulouse – F	GERONTOPOLE
RS PP6	Centre Hospitalier Universitaire Montpellier – F	CHRU
RS PP7	Unwersytet Medyczny W Lodzi – PL	LODZ
RS PP8	Universidad De La Iglesia De Deusto – SP	DEUSTO
RS PP9	Regional Health & Social Care Board of Northern Ireland – UK	HSCB
PP10	European Regional and Local Health Authorities Asbl – BE	EUREGHA
RS PP11	CARSAT Languedoc Roussillon – F	CARSAT

collaborations & synergies

74 EIP on AHA Reference Sites - 22 countries
12 Italian Reference Sites

EIP-AHA
A3 & B3

advantAGE
 MANAGING FRAILTY

CHRODIS
 ADDRESSING CHRONIC DISEASES AND
 HEALTHY AGING ACROSS THE LIFE CYCLE

SPRINTT
 Sarcopenia & Physical Frailty in older people:
 Multicomponent Treatment strategies

consenso



**EU Geriatric
 Medicine Society-
 EUGMS**

**Italian Geriatric Society-
 SIGG**

specific objectives

To design an **innovative, integrated model** for the **prevention and management of frailty and care of multimorbidity**

To **validate the model**: assess RS **systems and services** targeting frailty and multimorbidity – address citizen's/**patient's perceptions and needs**

To assess the **potential for the adoption, replication and sustainability of the model** (good practices & tools) in different organizational contexts

To **promote the dissemination** of the results: Regional, National, EU



definition of frailty

BIOMEDICAL VS. BIO-PSYCHOSOCIAL MODEL

Biomedical

Biological - age, sex

Health-diseases

Life styles - physical activity, nutrition...

Risk factors - smoke, alcohol...

Psyco-social

Well being (physical, psychological)

Independent living

Socialization

Resources - health care, social interaction, sport, leisure

Early identification (Risk factors)

Prevention of disability

REVERSIBILITY

beneficiaries perception of frailty and barriers to care

BRIDGING THE GAP

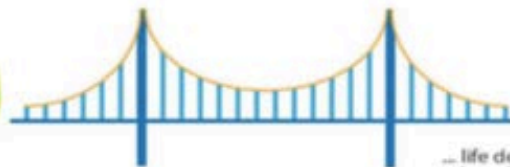
Need for independence

FRAILITY?

State of...



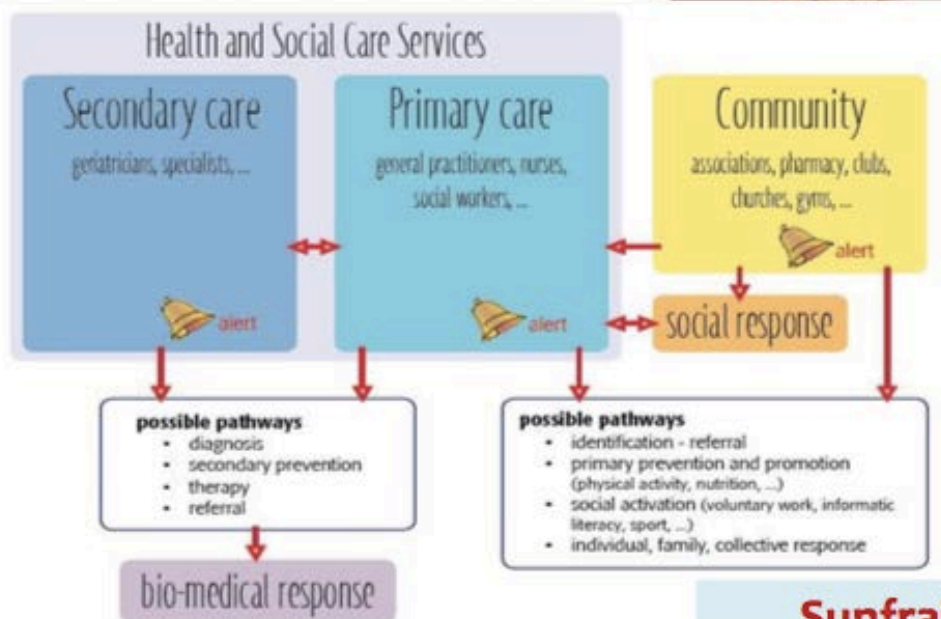
* playing with grandsons
* driving * dancing * walking



... life decline and extreme vulnerability characterized by weakness and decreased physiologic reserve contributing to increased risk for falls, institutionalization, disability, death.

- ✓ Risk factors
- ✓ Prevention
- ✓ Cultural, organizational barriers to services
- ✓ Multidisciplinary approach

Sunfrail Model of care on frailty & multimorbidity



Sunfrail Tool

Sunfrail Tool

QUESTIONNAIRE NUMBER		ID
Date and place		
PROFESSIONALS		
<input type="checkbox"/> Nurse <input type="checkbox"/> GPs <input type="checkbox"/> Other Professionals <input type="checkbox"/> Social Worker <input type="checkbox"/> Community Actor <input type="checkbox"/> Caregiver		
BENEFICIARIES		
Gender	Age	Level of education
<input type="checkbox"/> M	<input type="checkbox"/> 65-74	<input type="checkbox"/> Low (Without studies, Primary School)
<input type="checkbox"/> F	<input type="checkbox"/> 75-85	<input type="checkbox"/> Medium (Secondary school, or vocational degree)
<input type="checkbox"/> High (University, Master or PhD degree)		
Questions		
1. Do you regularly take 5 or more medications per day?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
2. Have you recently lost weight such that your clothing has become looser?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
3. Your physical state made you walking less during the last year?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
4. Have you been evaluated by your GP during the last year?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
5. Have you fallen 1 or more times during the last year?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
6. Have you experienced memory decline during the last year?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
7. Do you feel lonely most of the time?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
8. In case of need, can you count on someone close to you?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
9. Have you had any financial difficulties in facing dental care and health care costs during the last year?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

Sunfrail Tool main findings

The higher proportion of frailty alerts applies to **Polypharmacy, Functional and Cognitive Decline** items in **different settings**

In **Community - Primary Care Settings** the tool creates an alert on frailty in population **without evident signs of disability/unknown by services**

A higher prevalence of frailty is found in beneficiaries with **age group 75-85**

Citizens with a **lower education level** have a higher prevalence of frailty and greater **financial difficulties** of access (**Equity**)

Women have a **higher prevalence** of frailty than **men**

The positivity to **Sunfrail tool items** (Q1, Q3 and Q6) **is confirmed by specialist's tests**



elements of success



Sunfrail Tool

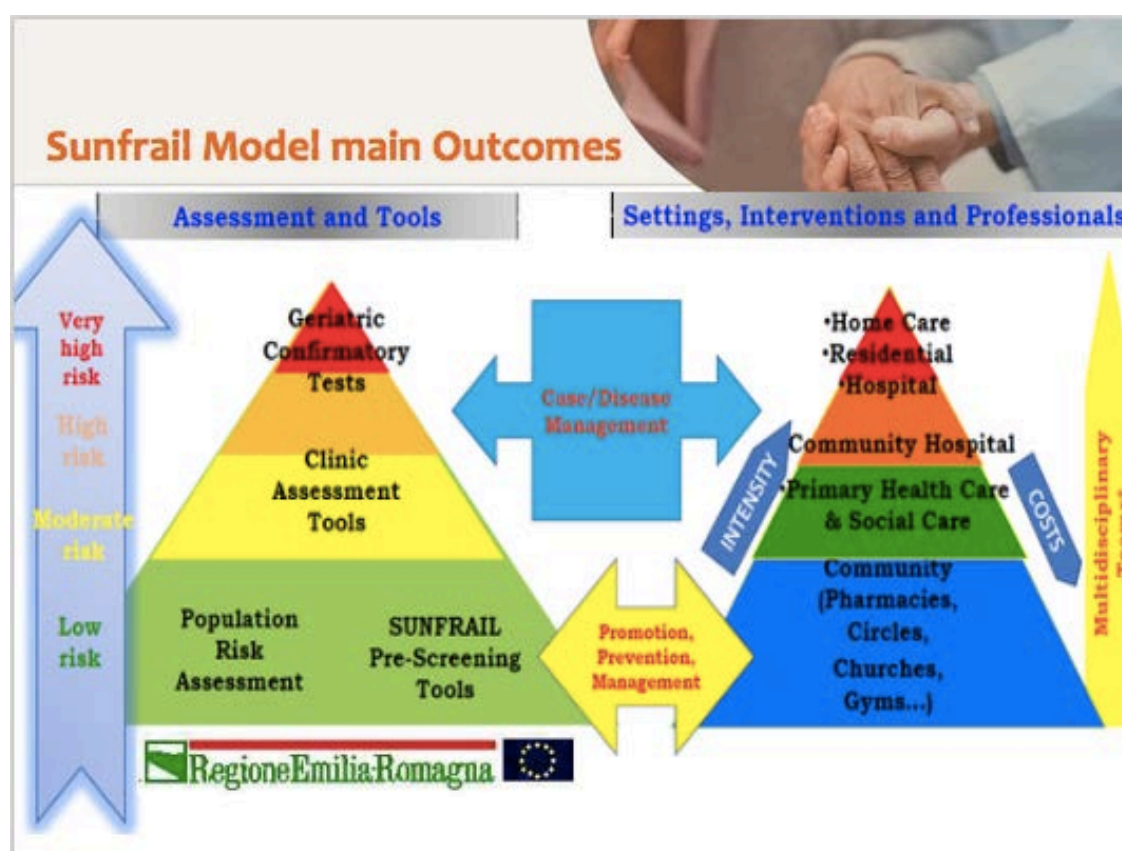
- Understandable** by professionals and beneficiaries
- Easy to use** by professionals and community actors
- Empowering** final **beneficiaries** (awareness - access)
- Intersectoral Collaboration** (health - social services) (**resources saving**)
- Multidisciplinary** approach to Frailty for HR development (**HR Tool**)

Applicability - Replicability - Sustainability

- Applied in other **EU projects** - **Local Health Services** - **GPs**
- A pilot study** on the Sunfrail Tool in the Netherlands (**R. Gobbens**)
- Requests for adoption:** **EU and IT Regions**
- Collaboration with **EU Joint Actions** (**Advantage - Chrodis**)

Sunfrail Model

Integration with RS Models of Care and Good Practices

potential for future applications

Further integration with **existent pathways** on frailty and multimorbidity (health and social services, community)

Deployment or adaption of **ICT tools** for the wider use of the Sunfrail tool

Link with **Population Risk Stratification** strategies and tools

Continue to work on the **multidisciplinary approach** to frailty and multimorbidity for human resources



Welcome!






Thank you for your attention!

Mirca Barbolini
Marcello Maggio
Maria Luisa Moro
SUNFRAIL Team

www.sunfrail.com
Sunfrail@regione.emilia-romagna.it


   

Sunfrail Tool





QUESTIONNAIRE NUMBER		ID
Date and place		
PROFESSIONALS		
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8. In case of need, can you count on someone close to you?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
9. Have you had any financial difficulties in facing dental care and health care costs during the last year?	<input type="checkbox"/> Yes <input type="checkbox"/> No	

flow chart



pathways

Request: GP visit	<input type="checkbox"/>
Request: Specialist-Geriatrician evaluation	<input type="checkbox"/>
Diagnostic Evaluation	<input type="checkbox"/>
Social Support	<input type="checkbox"/>
Proactive & Preventive	<input type="checkbox"/>
Interventions	<input type="checkbox"/>
Physical Exercise	<input type="checkbox"/>
Psychological and/or Cognitive support	<input type="checkbox"/>
Other Pathways	<input type="checkbox"/>
Relevant but not available	<input type="checkbox"/>
Non-relevant	<input type="checkbox"/>

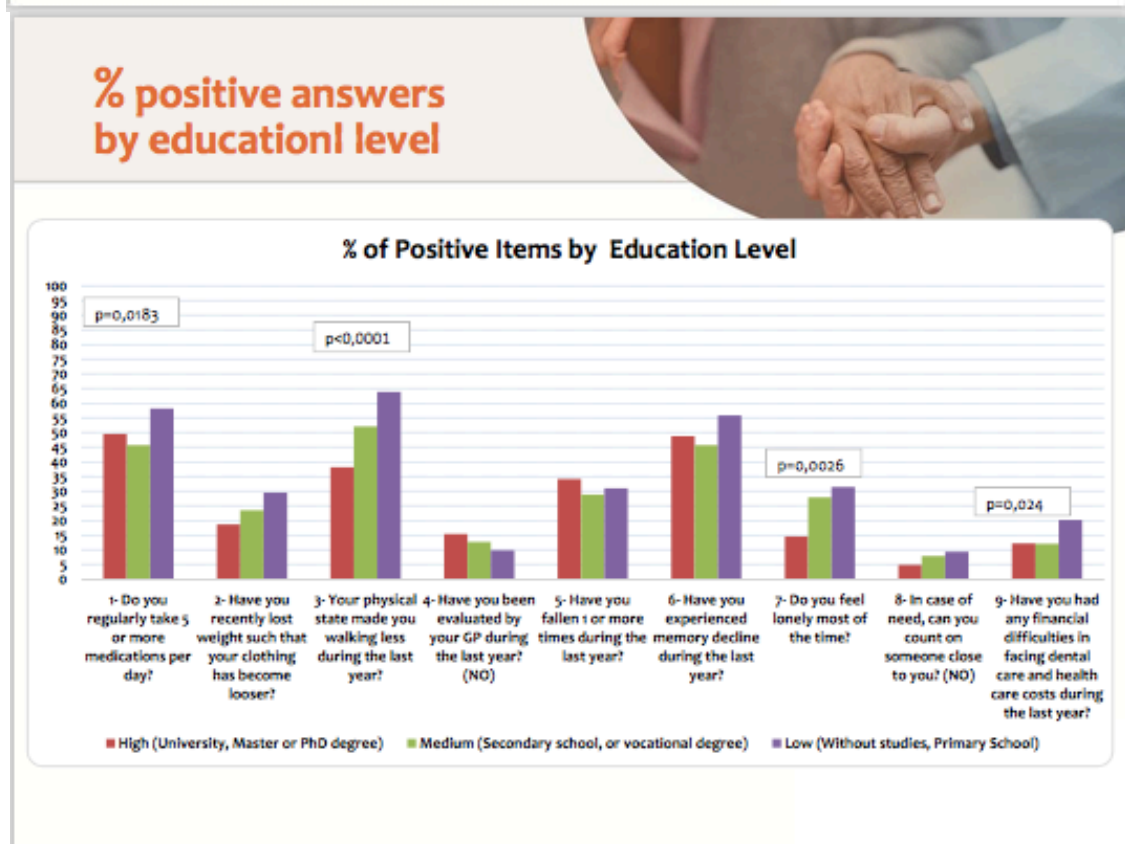
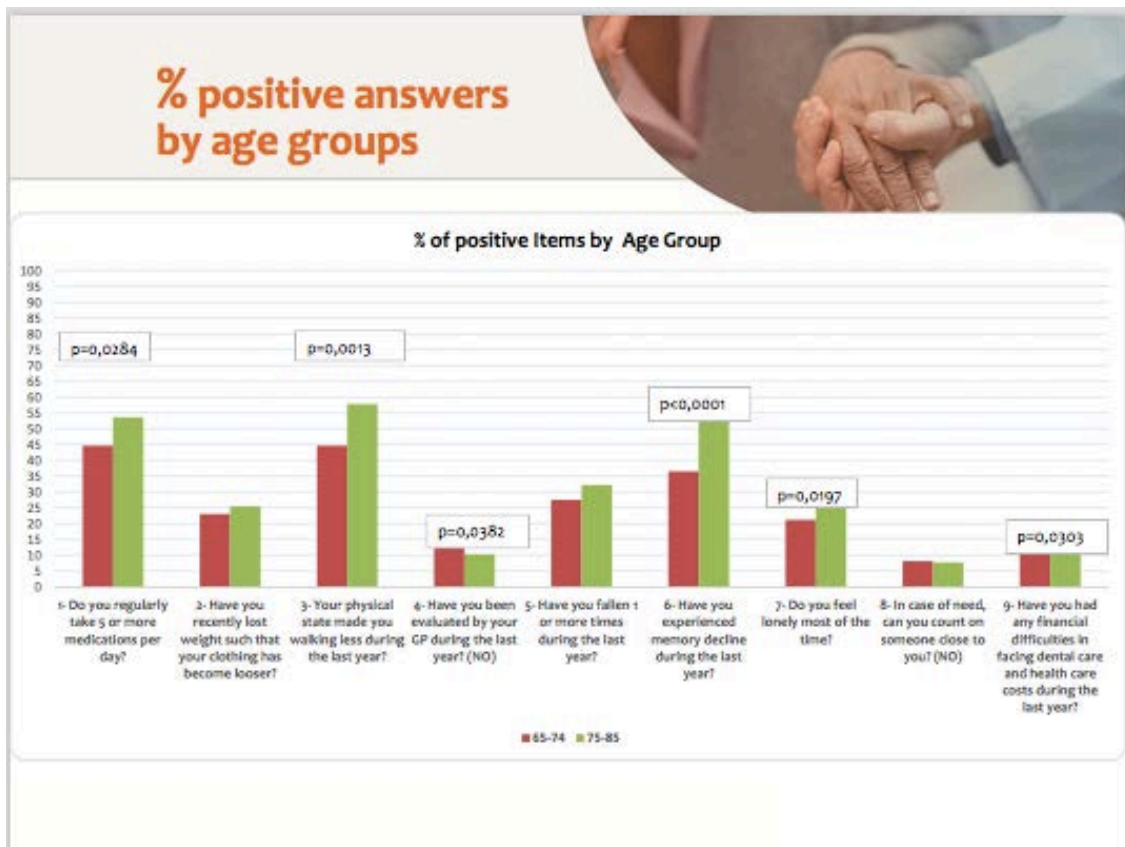
 

Sunfrail Tool preliminary results

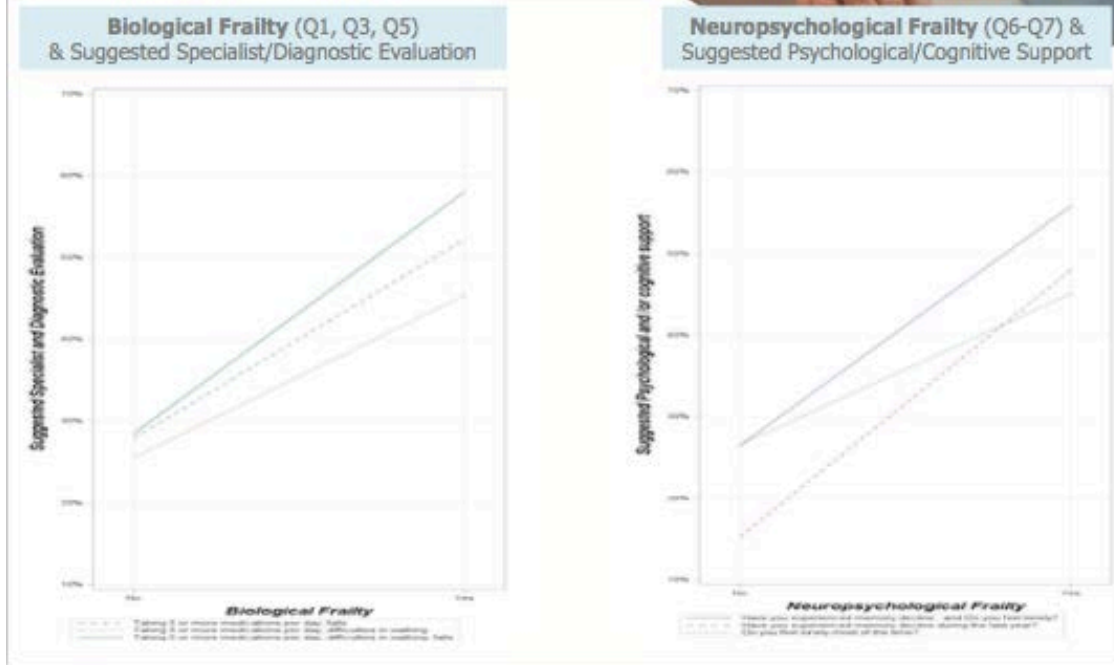
Study Population	N=651	%
Reference Sites		
Deusto University, Spain	105	16,13
Galliera Hospital, Liguria	194	29,8
HSCB, Northern Ireland	127	19,51
Medical University of Lodz, Poland	114	17,51
University of Naples Federico II	111	17,05
Beneficiaries		
Gender		
F	372	57,14
M	279	42,86
Age Class		
65-74	222	34,1
75-85	429	65,9
Education Level		
High (University, Master or PhD degree)	123	18,89
Medium (Secondary school, or vocational degree)	315	48,39
Low (Without studies, Primary School)	213	32,72

positive answers to the Sunfrail Tool items by settings

Questions	Total n=651	Secondary Care (Outpatient) (n=161)	Primary Care n=363	Community n=127
	%	%	%	%
1- Do you regularly take 5 or more medications per day?	50,54	65,22	42,7	54,33
2- Have you recently lost weight such that your clothing has become looser?	24,58	36,02	21,76	18,11
3- Your physical state made you walking less during the last year?	53,3	64,6	46,83	57,48
4- Have you been evaluated by your GP during the last year? (NO)	12,29	10,56	11,85	15,75
5- Have you fallen 1 or more times during the last year?	30,57	42,86	29,48	18,11
6- Have you experienced memory decline during the last year?	49,62	60,87	55,37	18,9
7- Do you feel lonely most of the time?	26,57	31,06	26,72	20,47
8- In case of need, can you count on someone close to you? (NO)	7,83	8,7	9,37	2,36
9- Have you had any financial difficulties in facing dental care and health care costs during the last year?	14,75	22,98	14,88	3,94

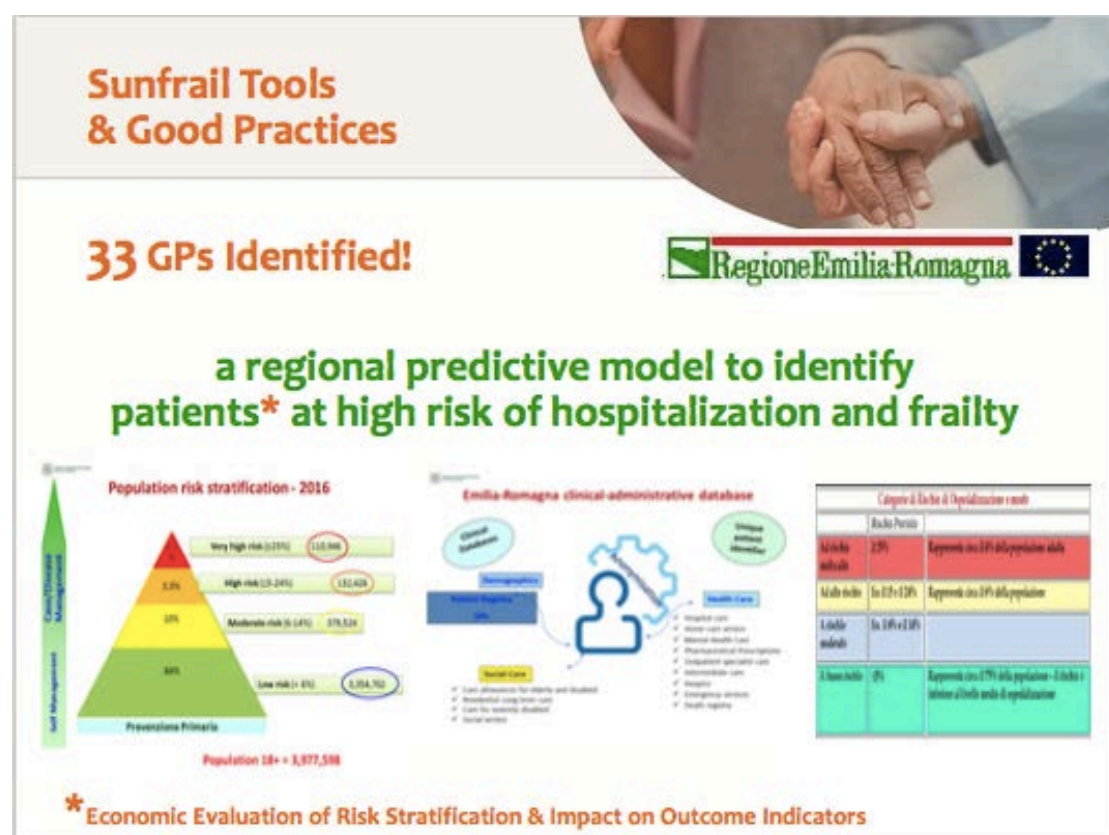
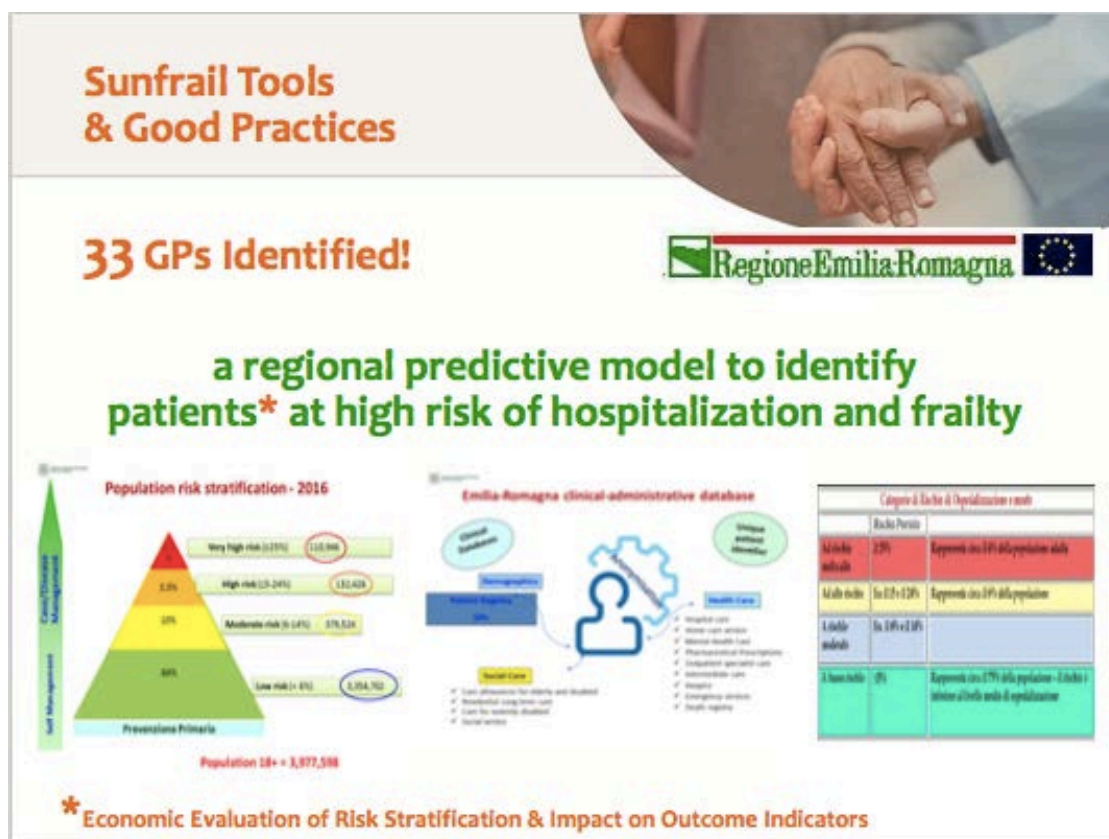


positive answers and suggested pathways





confirmation of the positivity of Sunfrail Tool Results with Specialist Tests

			Naples n=101						Poland n=114						R. Liguria N=194					
Questions			n	media	ds	diff*	ic95%	p-value	n	media	ds	diff*	ic95%	p-value	n	media	ds	diff*	ic95%	p-value
1- Do you regularly take 5 or more medications per day?	n. medication per day	no	33	2,818	1,467				17	3,529	1,772				109	2,954	1,754			
		yes	68	7,529	2,226	4,711	3,886-5,536	<0,0001	35	7,229	2,591	3,699	3,274-5,124	<0,0001	85	7,082	2,117	4,119	3,575-4,664	<0,0001
3- Your physical state made you walking less during last year?	4-m WS (0,8 m./sec.)	no	31	0,821	0,06				28	1,243	0,2047*				98	1,243	0,291			
		yes	70	0,365	0,127	0,456	0,408-0,503	<0,0001	24	1,069	0,281	0,174	0,041-0,307	0,003	94	0,995	0,305	0,254	0,169-0,338	<0,0001
6- Have you experienced memory decline during the last year?	MMSE (<24)	no	34	25,521	4,123				23	28,348	1,071				75	27,79	2,271			
		yes	67	20,556	3,597	4,965	2,531-7,399	0,002	29	28,655	1,518	0,693	-0,069-1,455	0,082	117	26,684	3,458	1,091	0,198-1,984	0,027



Presentation by Valentina BOTTARELLI



EURORDIS Operating Grant


An “enabler” for the rare disease
patient community

Valentina Bottarelli,
Public Affairs Director

“Limits and Potential of the Public Health Programme”
22 November, European Parliament, Brussels

EURORDIS.ORG

What is a rare disease?

OVER 6000 distinct rare diseases	Each one affects fewer than 1 IN 2000 PEOPLE	 All together, an estimated 30 MILLION PEOPLE are living with a rare disease in Europe and 300 MILLION worldwide
Affects between 6 % AND 8% of the population in the course of their lives 	NO CURE  for the vast majority of diseases and few treatments available	

2 EURORDIS.ORG 

The challenges

Rare diseases are chronic, progressive, degenerative, disabling and frequently life-threatening



- Patients and experts are few, geographically **scattered** and often **isolated**
- Patients are undiagnosed, misdiagnosed or wait years for a diagnosis
- Reliable **information is scarce**
- Resources are limited
- Lack of **treatments and challenges** to access adequate care
- **Fragmented research**, data and information
- High social impact and **marginalisation** within society at large and within healthcare systems designed for common diseases
- **Heavy psychosocial burden**: societal support is essential to patients and families to enable them to cope, be resilient, care for others

3

Rarity calls for action at European level

Although each disease itself is rare, the challenges facing people living with rare diseases are **common across diseases, and across borders**

No one country can solve alone the problems posed by rare diseases!
We need to bring together a **critical mass** of patients and medical experts, scientists and public health authorities – which does not exist in one single country

**Find solutions to
common problems**

Speak with one voice

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4

Rare diseases – priority in the Public Health Programme

- Rare diseases a priority in the PHP since 1998

RDs identified by the EC as a "unique area of very high European added value"

→ Only by pooling together at EU level fragmented resources & information, thus increasing knowledge about RD, that diagnostics and care can be improved – hence patients' health

- This translated into (examples)...

→ RAPSODY Project (resources on social and information services to patients, help lines for rare diseases, survey on access to care for rare disease patients)

→ POLKA Project (patients' needs and expectations on Centres of Expertise/ European Reference Networks)

→ EPIRARE Project (registries for rare diseases)



→ EUROPLAN Project (in support of Rare Disease National Plans)



→ Conference Grants (European Conferences on Rare Diseases)

→ Joint Actions on rare diseases



→ Operating grants



5

Rare diseases – priority in the Public Health Programme

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→ Only by pooling together at EU level fragmented resources & information, thus increasing knowledge about RD, that diagnostics and care can be improved – hence patients' health

- PHP2014-2020 "Health for Growth":

4. Facilitate access to better and safer healthcare for Union citizens

4.1 European Reference Networks

4.2 Rare diseases

4.3 Patient safety and quality of healthcare

4.4 Measures to prevent antimicrobial resistance and control healthcare-associated infections

4.5 Implementation of Union legislation in the fields of tissues and cells, blood, organs

4.6 Health information and knowledge system to contribute to evidence-based decision-making

Examples of expected results

Increased use of **evidence-based practices** in Member States

Integrated coherent approaches in Member States preparedness plan, **improved**

surveillance and response to cross-border health threats

Increased sustainability of health systems

Creation of **European Reference Networks**, for example on rare diseases

6

EURORDIS.ORG

EURORDIS - Who are we?

Our vision

Better lives and cures for people living with a rare disease

Our mission

EURORDIS-Rare Diseases Europe works across borders and diseases to improve the lives of people living with a rare disease

By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.



EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 700 rare disease patient organisations from more than 60 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe.

7

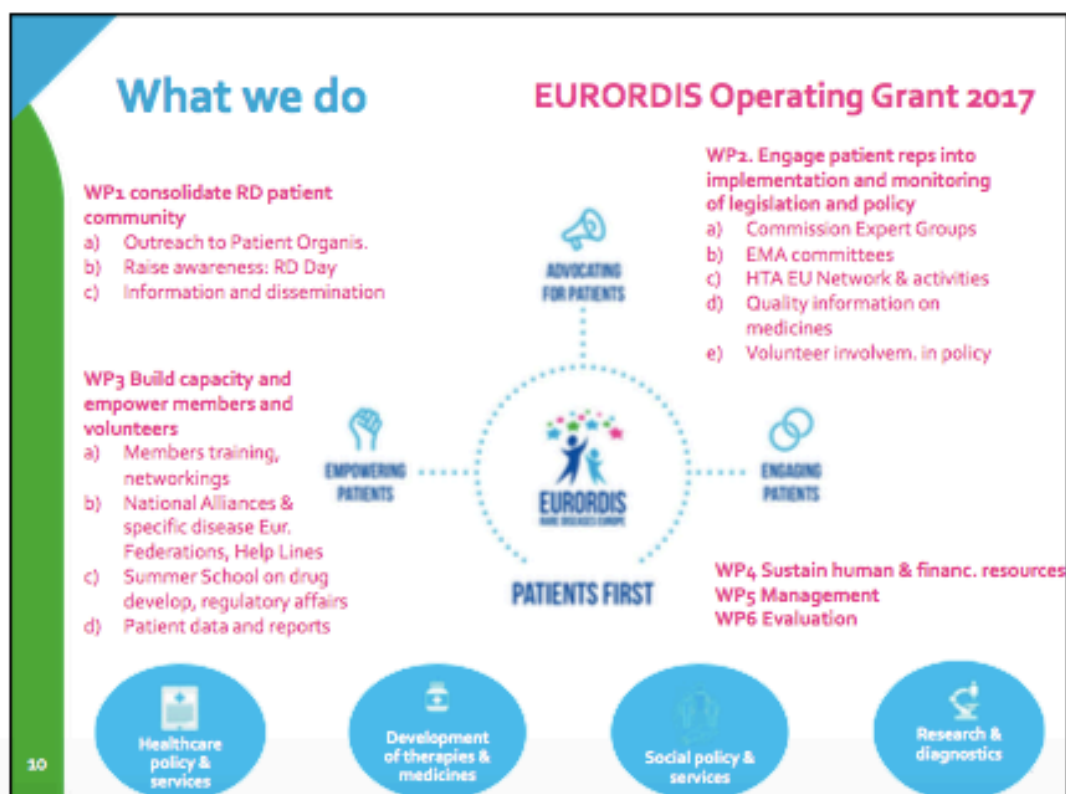
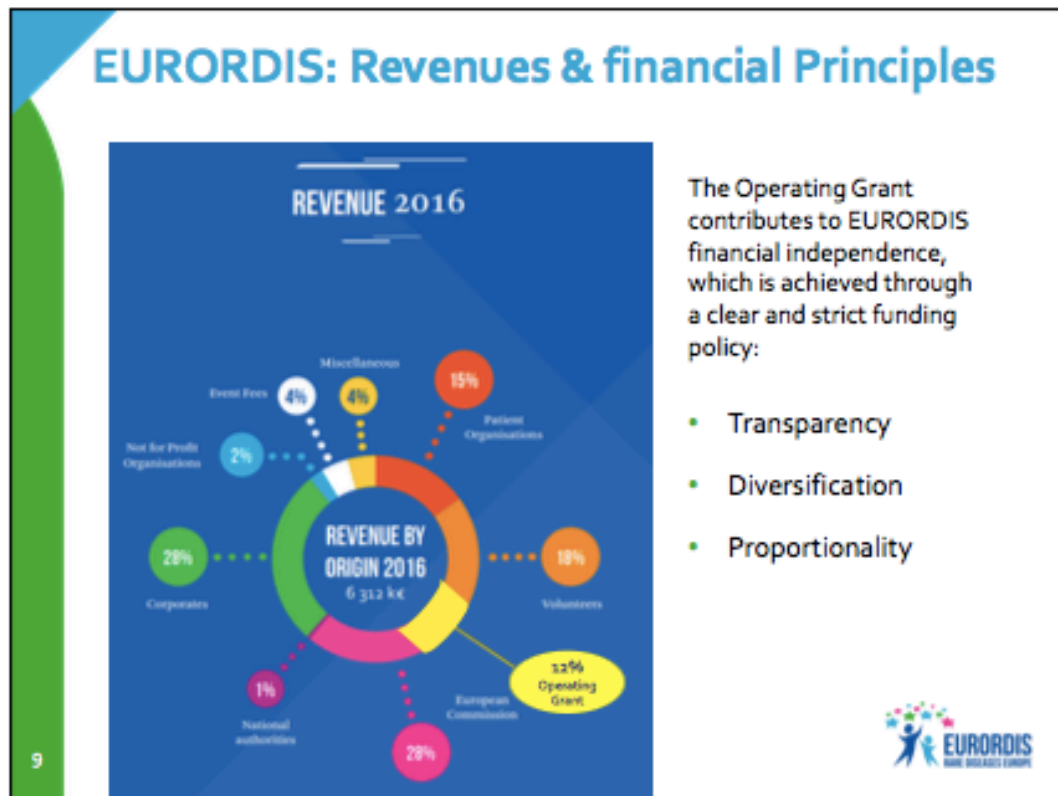
1. Operating Grant

- Since 2009 EURORDIS was granted an Operating Grant for 8 years in a row
- Since 2015, a multiannual Framework Agreement is established with annual applications
- Current Framework Agreement 2015-2017 coming to an end
- New Framework Agreement 2018-2021

8

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Rare Disease Day



RAREDISEASEDAY.ORG


- Held on the last day of February each year
- An occasion to raise public and policy-maker awareness of rare diseases
- Created by EURORDIS and its National Alliances
- Growing since 2008 and becoming global: 94 countries and regions worldwide in 2017



11 EURORDIS.ORG rarediseaseday.org


→ WP1 Consolidate patient community – Awareness Raising

EURORDIS Summer School



EURORDIS SUMMER SCHOOL

- Started 2008, over 400 patient representatives and researchers have been trained, coming from 40+ different countries and representing 75+ diseases
- Since 2015, open also to academic researchers
- So far, 5-day annual training on:
 - Clinical Trials & Medicines Development
 - EU Regulatory Processes & EMA
 - HTA, Reimbursement, Patient Access
 - Translational & International Research
- Alumni involved in regulatory processes at the EMA and/or in collaboration with sponsors and/or as EURORDIS' Volunteers



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→ WP3 Build Capacity & Empower members

Patient involved in EMA Committees

COMP: Committee for Orphan Medicinal Products

- 1 EURORDIS representatives (Vice-Chair) + 1 Observer

PDCO: Paediatric Committee

- 2 EURORDIS representatives (full member & alternate)

CAT: Committee for Advanced Therapies

- 1 EURORDIS representative (full member)

PCWP: Patients' and Consumers' Working Party

- 2 EURORDIS representatives (full members)

Scientific Advice & Protocol Assistance

CHMP: Committee for Human Medicinal Products




→ WP2 Engage patient representatives

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Operating Grant – an “enabler”

The Operating Grant helped EURORDIS contribute to EU policy. For ex.:

- **Health literacy**
 - Review of 215 documents for public information (EPARs, PLs, PSOs) within EMA procedure
- **Improving access to therapies and care**
 - Access Campaign – survey identify access issues to both therapies and care in general
 - Survey “Tell us how you take your medicine” (on off-label use in rare diseases)
- **Cross-border cooperation in HTA**
 - Representation of patients as stakeholders in HTA network, contribution to EUnetHTA guidelines
 - Identification of patients to be invited as observers in the SEED early dialogues
- **European Reference Networks (ERNs)**
 - Regular information to members and capacity building with dedicated training and meetings
 - Membership structuring to reflect rare disease groupings in ERNs
 - Policy work within Commission Expert Group on RD and RD Joint Action



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Operating Grant – leverage effect

Activities funded by the OG allow EURORDIS to **liberate resources to perform other activities to fulfill its mission:**

- Contribute actively to policy-making with advocacy action aimed to patient-centred decision-making
- Empower patients and members with capacity building activities, networking and information
- Raise awareness on rare diseases and people and families living with rare diseases
- Participate to and initiate other projects

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Operating Grant – essential & added value for NGOs

- Necessary tool to fund **recurring operations** rather than ad hoc actions for organisations whose missions fits with the EU Public Health Programme
- Provides ability to deliver **impactful action and improve quality of work**
- Enables the organisation to **facilitate relationship** between citizens and civil society organizations (patient groups) and European policy-makers
- Helps **operationalise objectives and policies of the European Commission**, connecting different stakeholders, bringing patients at core of policies



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Operating Grant – essential & added value for NGOs

Securing resources through **public funds** should help ensure:

- Longer-term **stability**
- **Diversity** of funding resources
- Greater **independence** from private funders

Hence:

- **Fair and objective representation of economically weak players in society** (patients)
- **Recognition of central role of civil society organisations in EU health policy making**

"to address the imbalances and asymmetry of power that affect patient engagement" Kaisa Immonen, European Patient Forum, Co-chair of Patient and Consumer Working Party at EMA

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Operating Grant – Challenges

- EU and national health policy environment increase complexity, while funds are reduced (less beneficiaries, smaller proportion of their budgets)
- Lack of clarity and **limited transparency** on the evaluation process
- Decision-making process and timelines generate **instability**: shifted decision making at the end of the financial year leads to nerve-wracking management
 - no private business would ever work with this level of uncertainty !
 - in case of negative decisions operations are seriously threatened
- Framework Agreement (multiannual) in addition to annual applications for Specific Grant Agreements do not generate greater stability, only additional burden
- Late payments requires cashflow, uncertainty imposes large reserves
- Participation to political cooperative projects (Joint Actions) de facto excluded for NGOs: less opportunities to contribute to policy debates and relevant decision-making & less funds available (hence greater relative weight of Operating Grants as a consequence)

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Conclusions - Operating Grant for Rare Disease Patients & Health Programme

Overcoming fragmentation
Creating a critical mass
Learning from each other
Working together



An illustration of how **EU action in health** can provide **added value to national efforts** and thus **help improve health of European citizens** and **reduce health inequalities**

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Conclusions – Health Programme: build on positive results & strengthen

- **Building on positive results** and **scale up**, with replication and feedback loop into the policy environment. Previous Health Programmes :
 - Had impact well beyond their financial size: high return on investment !
 - Exchange of knowledge between Member States would not have otherwise occurred
 - Allowed activities where the budget restrictions would not have made them possible
 - Important for ensuring human-right based approach to health policy
- Crucial that **Health Programme continues and gets stronger**:
 - To face ever increasing challenges facing public health and healthcare systems in Europe cannot be tackled effectively by countries acting alone
 - To fund initiatives underpinning EU health policy coordination to complement, support and add value to the national policies of Member States
 - To meet legitimate expectation of patients and citizens and help build health systems that are more people and patient-centred and accessible

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