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Mid-term evaluation of the Third Health Programme (2014-2020)

Fields marked with * are mandatory.

INTRODUCTION

The EU ensures that human health is protected as part of all its policies, and to work with its Member States to improve public health, prevent human illness and eliminate sources of danger to physical and mental health. However, the EU Member States have the primary responsibility for formulating and implementing health policy and delivering healthcare services. The EU's competence only extends to supporting, coordinating or supplementing actions of the Member States.

One of the main ways in which the EU supports, coordinates and supplements actions by the Member States is the third programme for the Union's action in the field of health (2014-2020) (hereinafter: "3HP"). The 3HP provides financial support for actions to address a number of important health-related challenges facing European citizens, governments and health systems. The 3HP supports action across the EU from public authorities, research and health institutions, NGOs, international organisations and − in certain cases − private companies. The total budget for the seven years of its duration is €449.4 million. The 3HP addresses major health challenges facing MS from risk factors (such as use of tobacco and harmful use of alcohol) to chronic and rare diseases, responding to cross border health threats (e.g. Ebola and Zika viruses) as well as ensuring innovation in public health to name just a few areas. For more information on the 3HP, please visit the websites of DG SANTE or CHAFEA.

This consultation is an opportunity for any interested parties to express their views and opinions on the 3HP. It is a part of the ongoing mid-term evaluation of the 3HP. The consultation covers:

- The objectives and priorities of the 3HP, and the extent to which these are appropriate and in line with health needs in the EU
- The way the 3HP is implemented, and the extent to which this is effective and efficient
- The overall added value and usefulness of the 3HP

The results of the public consultation will be used together with other evidence to inform the mid-term evaluation of the 3HP. The European Commission will publish a Staff Working Document, including a summary of the results of the consultation, in the second half of 2017.

* Privacy Statement

Before completing the form, please read carefully the <u>privacy statement to conform to European data</u> <u>protection regulations</u>.

I have read and accept the terms and conditions related to this meeting

In case you wish to contact the Unit responsible for the event, please send an email to: <u>SANTE-HEALTH-PROGRAMME@ec.europa.eu</u>

I. KNOWLEDGE OF AND EXPERIENCE WITH THE 3HP

1.1. How would you describe the extent of your knowledge of:

	Detailed, in-depth knowledge	Some knowledge	Only very basic knowledge	No knowledge at all
*EU health policy?	•	•	•	0
*The 3HP?	•	0	0	0

*1.2. Are you working on health issues that are closely related to (any of) the ones supported I	by
the Health Programme?	

(0)	Yes
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*1.3. Are you aware of any activities that were funded by the 3HP that are relevant to your work?

Y	es
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O No

O No

1.4. Have you ever consulted, used, or participated in any of the results, services or products stemming from activities supported by previous Health Programmes? Please tick the following examples, as appropriate:

The Commission encourages dissemination of Health Programme outputs and results, however linking to the following external websites from this webpage should not be taken as an endorsement of any kind by the European Commission.

V	The European Code Against Cancer
	European screening guidelines on Breast cancer
	European screening guidelines on Colorectal cancer
	European screening guidelines on Cervical cancer
V	The Orphanet database and recommendations for rare diseases
	The Eudamed database for medical devices (only accessible to Member State authorities)
	The Euripid database for the pricing of medicines
	Materials on health technology assessment
	Training packages, e.g. on <u>cancer screening</u> , <u>migrants' and refugees' health</u> , capacity building in the preparation and response against health threats in \underline{air} and \underline{sea} travel
V	Best practices for tackling health inequalities
	Best practices for the diagnosis and treatment of <u>HIV/AIDS</u> , tuberculosis and <u>hepatitis</u>
	Scientific Opinions from the Independent Scientific Committees
	Advice from the Expert Panel for investing in health
	Information campaigns (e.g. <u>Ex-smokers are unstoppable</u>)
V	Reports (e.g. <u>Health at a Glance Europe</u> , The Economics of prevention, Country Health Reports, EU
	Health Report, different Reports on the monitoring of health strategies on nutrition, alcohol etc.)
	Comparable health data (e.g. <u>ECHI indicators</u>)
1	Others

Others, please explain

SIOPE has been representing the pan-European paediatric cancer community in initiatives stemming from the European Commission Communication on Action Against Cancer: European Partnership. Thus, SIOPE was partner in the European Partnership for Action Against Cancer (EPAAC), where it coordinated the development of the 'European Standards of Care for Children with Cancer' that outline the essential organisational guidelines for paediatric cancer units across Europe. Now translated in more than 15 languages and monitored for implementation by SIOPE, the European Standards represent a crucial instrument developed with the support of the EU health programme to ensure the best possible care for childhood cancer and to address inequalities in the treatment and care of young patients across Europe. Under the current 3rd Health Programme, SIOPE has been building on the Standards of Care in the ExPO-r-Net project led by CCRI, Austria, helping identify hubs of coordination in Central and Eastern Europe and build a pilot European Reference Network in Paediatric Cancer. The Standards are thus an important foundation of the approved ERN PaedCan, and are also underlying the SIOPE-led work package in the Joint Action on Rare Cancers.

* 1.5. Have you or the organisation / institution you represent ever applied for funding from the 3HP and/or its predecessors?

- Yes, I/we have applied for funding from the 3HP
- No, I/we have never applied for funding from the 3HP.
- Don't know

1.6. If you have never applied for funding from the 3HP, please tell us why (tick all that apply)

- The opportunities and activities are not relevant for me and/or my organisation
- Lack of information on opportunities
- Lack of information on how to apply
- The co-funding rates are not attractive enough
- Excessive administrative burden
- Lack of language skills
- Lack of partners in other European countries
- Other, please specify

Other (please specify)

SIOPE successfully applied as part of the ExPO-r-Net project consortium and has been endorsed as associated partner in the Joint Action on Rare Cancers and previously the EPAAC.

1.7. The 3HP is supporting cooperation at EU level between relevant health organisations, national health authorities, academia and non-governmental bodies. To what extent do you agree with the following statements?

	Strongly	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know
*The cooperation is essential and should be maintained	•	•	•	•	•	0
*The 3HP should be expanded to include other health areas	•	•	•	•	•	0
*In practice, the 3HP's results (at least at this mid- term stage) are not visible and the cooperation should be abandoned		©	©	©	•	©

* 1.8. In your opinion, what do you consider to be the main way(s) in which the 3HP is contributing (or could contribute) to addressing health-related challenges?

SIOPE strongly appreciates the collaboration ongoing under the 3rd Health Programme on initiatives targeting cancer and paediatric cancer specifically, such as in relation to the European Reference Networks, the ExPO-r-Net project and the Joint Action on Rare Cancers. These actions aim to address the important issues in the paediatric cancer sector that include major inequalities in access to standard treatment and expertise, urgent need to ensure appropriate follow-up of cured patients and manage long-term treatment effects, and lack of access to therapeutic innovation. SIOPE believes that further targeted projects and core funding support will be needed to ensure that the magnitude and specificities of these challenges are addressed in an appropriate manner. Indeed, childhood cancer is the leading cause of children' s death by disease over the age of 1 in Europe, and cancers in children and adolescents are specific and often different from adult cancers in terms of disease profiles, treatment modalities, and approaches to care. The SIOPE Long-Term Strategy - A European Cancer Plan for Children and Adolescents http://www.siope.eu/SIOPE_StrategicPlan2015/#, developed with prior EU support and in cooperation with parents, patients and survivors, presents an overview of the most pressing challenges in the sector and proposes implementation models by which these could be met.

1.9. What are the main aspects (if any) that need to be changed or improved in your opinion?

Childhood cancer is the leading cause of children's death by disease over the age of 1 in Europe. Whereas individual types of cancers in children and adolescents may be rare, taken together paediatric cancers represent a significant public health issue. As a result of these two characteristics - rarity combined with important shared burden across the EU and beyond - paediatric cancer patient stand to gain considerably from cooperation on health projects and programmes across borders. Thus, further initiatives under the EU Health Programme should address paediatric cancer specifically and with increased funding, including core funding. This is necessary to tackle the urgent issues in the sector - which include unequal access to quality treatment and care, lack of therapeutic innovation, and the burden that survivors face long into adulthood - and to develop the capacity of paediatric cancer actors to interact with EU processes and foster meaningful representation of the sector.

II. THE 3HP OBJECTIVES AND PRIORITIES

The 3HP aims to address a number of important health-related challenges facing EU citizens, governments and health systems. To do this, it pursues a series of objectives and thematic priorities, please see the factsheet about the 3HP for more information.

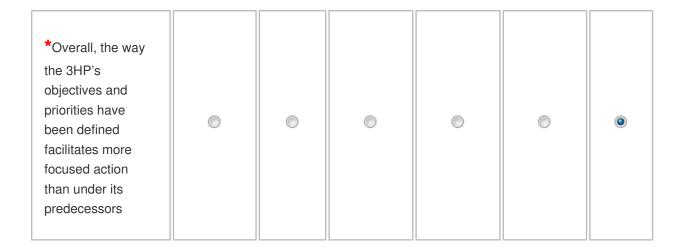
2.1. Do you think the EU should provide funding for actions in order to...?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know
*promote health, prevent diseases, and foster supportive environments for healthy lifestyles	•	0	©	•	•	•
*protect citizens from serious cross- border health threats (Zika and Ebola outbreaks)	•	•	•	•	•	•
*contribute to innovative, efficient and sustainable health systems	•	0	•	•	•	•
*facilitate access to better and safer healthcare for EU citizens	•	0	©	•	•	•
*contribute to addressing health inequalities and the promotion of equity and solidarity	•	©	©	©	©	•

2.2. To what extent do you agree with the following statements about the 3HP?

Strongly agree Ag	Agree Neither agree nor disagree	Disagree	Strongly disagree	Don't know
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*The 3HP's objectives and priorities are clear and easy to understand	©	•	©	©	©	0
*The 3HP's objectives and priorities are in line with the main health needs in Europe and are appropriate for addressing the key issues and challenges	•	•	•		•	•
*The objectives and priorities of the 3HP are consistent with health policy objectives in my country	•	•	•	•	•	•
*The more explicit consideration of economic resources and constraints in the objectives of the 3HP (compared with its predecessors) is appropriate	©	©	•	•	•	•
*The objectives and priorities of the 3HP are consistent with wider EU policy objectives, including the Europe 2020 strategy	©	•	•	•	•	•



2.3. If you have any concerns about the relevance and coherence of the 3HP and its objectives, please briefly summarise them here.

SIOPE stresses the need to address the specific priority health needs of children and adolescents. In terms of biology and approaches to treatment and care, they should not be considered as small adults and should be allocated appropriate programmes and resources. EU funding is key to address the most urgent needs of children and adolescents — the future of Europe, especially where diseases are characterised by low incidence at national level and where cross—border cooperation is thus of mutual benefit, such as in the field of paediatric cancer.

2.4. The 3HP contains 23 thematic priorities, gathered under four specific objectives:

- 1. Promote health, prevent diseases, and foster supportive environments for healthy lifestyles
- 2. Protect citizens from serious cross-border health threats
- 3. Contribute to innovative, efficient and sustainable health systems
- 4. Facilitate access to better and safer healthcare for EU citizens

Please select up to five priorities that you consider to be the most important, and up to five that you consider to be not relevant.

	Most important	Not relevant
1.1. Risk factors such as use of tobacco and passive smoking, harmful use of alcohol, unhealthy dietary habits and physical inactivity	0	0
1.2. Drugs-related health damage, including information and prevention	0	0
1.3. HIV/AIDS, tuberculosis and hepatitis	0	0

1.4. Chronic diseases including cancer, age-related diseases and neurodegenerative diseases	•	0
1.5. Tobacco legislation	0	0
1.6. Health information and knowledge system to contribute to evidence-based decision-making	0	0
2.1. Additional capacities of scientific expertise for risk assessment	0	0
2.2. Capacity-building against health threats in Member States, including, where appropriate, cooperation with neighbouring countries	©	0
2.3. Implementation of EU legislation on communicable diseases and other health threats, including those caused by biological and chemical incidents, environment and climate change	©	0
2.4. Health information and knowledge system to contribute to evidence-based decision-making	0	©
3.1. Health Technology Assessment	0	0
3.2. Innovation and e-health	•	0
3.3. Health workforce forecasting and planning	0	0
3.4. Setting up a mechanism for pooling expertise at EU level	•	0
3.5. European Innovation Partnership on Active and Healthy Ageing	0	0
3.6. Implementation of EU legislation in the field of medical devices, medicinal products and cross-border healthcare	•	0
3.7. Health information and knowledge system including support to the Scientific Committees set up in accordance with Commission Decision 2008/721/EC	©	0
4.1. European Reference Networks	•	0
4.2. Rare diseases	0	0
4.3. Patient safety and quality of healthcare	0	0
4.4. Measures to prevent antimicrobial resistance and control healthcare-associated infections	0	0
4.5. Implementation of EU legislation in the fields of tissues and cells, blood, organs	0	0
4.6. Health information and knowledge system to contribute to evidence-based decision-making	0	0

2.5. If there are any other important thematic priorities you believe the 3HP should support in the future, or amendments to the existing priorities, please list them here.

SIOPE would like to re-iterate the call to increase opportunities for specific paediatric disease areas incl. paediatric haemato-oncology. Childhood cancers are a leading cause of children's death by disease in Europe and as a collection of rare diseases are best addressed through coordinated efforts of Member States. The general programmes on cancer are not always fully equipped to address the specific needs of the sector as children and adolescents possess a series of characteristics that make treatment and care approaches different from those in adults. The SIOPE Long-Term Strategy http://www.siope.eu/SIOPE_StrategicPlan2015/#, developed with prior EU support and in cooperation with parents, patients, and survivors, presents an overview of the most pressing challenges for childhood cancer in Europe as well as implementation models by which these challenges could be met.

III. IMPLEMENTATION

The 3HP has a total budget of €449.4 million (2014-2020), which is used to support:

- Cooperation projects at EU level (via project grants)
- Actions jointly undertaken by Member State health authorities
- The functioning of non-governmental bodies (via operating grants)
- Cooperation with international organisations (via direct grants)
- Studies and other service contracts to cover specific needs related to the support of EU health policies

The 3HP is implemented on the basis of Annual Work Programmes developed by the European Commission in consultation with representatives of the countries that participate in the 3HP (via the Programme Committee). An executive agency (CHAFEA) is responsible for implementing the Programme; its tasks include issuing calls and evaluating proposals, disbursing payments, monitoring actions and disseminating the results. National Focal Points in Member States promote opportunities arising through the Programme. An infographic showing the different roles can be found here.

3.1. To what extent do you agree with the following statements about the implementation of the 3HP?

Strongly	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know
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*The types of funding mechanisms used by the 3HP are appropriate to achieve the objectives of the programme	©	•	©	•	•	0
*The prioritised actions in the Annual Work Programme permit the optimal involvement of health actors and stakeholders' groups by making appropriate use of the different funding mechanisms		•	•	•	•	•
*The 3HP includes appropriate measures to involve all Member States, including those with lower incomes	©	•	©	•	•	•
*The more explicit consideration of economic resources and constraints in the objectives of the 3HP (compared with its predecessors) is appropriate	©	©	©	•	•	•
*The level of financial support that the 3HP offers is appropriate to address its objectives	•		•	•	•	•

- 3.2. If you have any (additional) concerns about the 3HP and the way in which it is implemented, please briefly summarise them here and provide us with an indication of which area(s) they correspond to (tick all that apply):
 - Eligibility / funding arrangements
 - Application process
 - Administrative burden
 - Dissemination of results
 - Other (please specify)

Other (please specify)

Particularly with regards to Joint Actions, one could suggest exploring an endorsement process where pan-European NGOs could take part without the condition of endorsement by a particular Member State, due to their pan-European nature. This would be viable because most such NGOs are legal entities in a member state whilst genuinely representing pan-European perspectives.

3.3 To what extent do you agree with the following statement about the level of awareness of the 3HP?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know
*The results of actions funded by the 3HP are sufficiently disseminated and promoted to those who might be able to make use of them	©	•	•		•	•

3.4. Do you have other specific views that could not be expressed in the context of your replies to the above questions?

SIOPE strongly appreciates the cooperation under the Health Programme which has been instrumental in achieving some of the milestone deliverables for the paediatric cancer community - the European Standards of Care for Children with Cancer, the ERN PaedCan, and the cooperation with the adult sector to address the challenges of cancers in children and adolescents in the context of the JARC. SIOPE would also like to stress the success of the CanCon Joint Action which we have been following actively although with indirect involvement. We thus overall rate our experience with the Health Programme positively. However, due to the major public health burden of childhood cancer in Europe, the potential to address it more and better through coordinated cross-border cooperation, and the age-specific unaddressed challenges that remain, we would like to recommend that further funding is allocated to projects, programmes, and organisations working on cancer in children and adolescents. As one example of a possible venue of collaboration, SIOPE welcomes the announcement of a new Joint Action to follow CanCon and would be keen to contribute actively

IDENTIFICATION OF RESPONDENT

	ease indicate whether you are responding to this consultation as an individual or on behalf of e of the following types of organisations / institutions?
	Individual / private person
[Public authority (national, regional or local)
	International organisation

- Academic / research organisation
- Professional association or trade union
- Non-governmental organisation
- Private company
- Other, please specify

^ Plea	se state your country of residence/establishment
0	Austria
•	Belgium
	Bulgaria
	Croatia
	Cyprus
	Czech Republic
	Denmark
	Estonia
	Finland
	France
	Germany
	Greece
	Hungary
	Ireland
	Italy
	Latvia
	Lithuania
	Luxembourg
	Malta
	Netherlands
	Poland
	Portugal
	Romania
	Slovak Republic
	Slovenia
	Spain
0	Sweden
0	United Kingdom
	Other
	sent in comments in a language other than English, please indicate in which language you
have	replied.

*Which of the following best describes the field in which you or the organisation or institution you are representing are mainly active?
Health / public health policy making and planning
Provision of healthcare services
Health professional(s)
Health research / education
Patients and health service users
✓ Other, please specify
Other, please specify
The SIOPE governance includes a Clinical Research Council (CRC) representing all clinical trial groups and national societies for paediatric haematology-oncology in Europe. In addition, SIOPE has a Memorandum of Understanding agreement with the parents and patients organisation Childhood Cancer International (CCI) to ensure a unified approach across all areas.
^k First name
Samira
* Last name
Essiaf
^k Job title
Chief Executive Officer
Your organisation's name (where relevant)
SIOPE - the European Society for Paediatric Oncology
The number of members your organisation represents (where relevant)
1687 members in 34 countries across Europe

Countries where your organisation is present (where relevant)

1687 members in 34 countries across Europe

- *If replying on behalf of an organisation or institutions, is your organisation or institution registered in the EU Transparency Register?
 - Yes
 - O No
 - Not applicable

If yes please indicate your Register ID number

122803916413-09

If you are responding on behalf of an organisation or institution, please register in the <u>Transparency Register</u>. If your organisation/institution responds without being registered, the Commission will consider its input as that of an individual and will publish it as such.

- * Please indicate your preference for the publication of your response on the Commission's website:
 - I consent to publication of all information in my contribution, including my personal data
 - I do not consent to the publication of my personal data as it would harm my legitimate interests. My contribution may be published in an anonymous form
 - I prefer to keep my contribution confidential. (it will not be published, but will be used when analysing the results of the consultation)

(Please note that regardless of the option chosen, your contribution may be subject to a request for access to documents under <u>Regulation 1049/2001 on public access to European Parliament, Council and Commission documents</u>. In this case the request will be assessed against the conditions set out in the Regulation and in accordance with applicable data protection rules.)

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- I don't agree, please keep my contribution as specified under the abovementioned terms, but only for internal use in the Commission

Useful links

<u>Factsheet on the Third Health Programme (http://ec.europa.eu/health/programme/docs/factsheet_healthprogramme2014_2020_en.pdf)</u>

Regulation (EU) No 282/2014 on the establishment of a third Programme for the Union's action in the field of hea (2014-2020) (http://data.europa.eu/eli/reg/2014/282/oj)

Summaries of the Annual Work Programmes for 2014 (http://ec.europa.eu/health/programme/docs/wp2014_annex_summary_en.pdf)

Summaries of the Annual Work Programmes for 2015 (http://ec.europa.eu/health/programme/docs/wp2015_summary_en.pdf)

Summaries of the Annual Work Programmes for 2016 (http://ec.europa.eu/health/programme/docs/wp2016_summary_en.pdf)

Ex-post evaluation of the 2nd Health Programme 2008-2013 (http://ec.europa.eu/health/programme/policy/2008-2013/evaluation_en.htm)

Contact

SANTE-HEALTH-PROGRAMME@ec.europa.eu