



Healthier Together – EU NCD Initiative

The EU NCD Initiative addresses five strands: a) cardiovascular diseases, b) diabetes, c) chronic respiratory diseases, d) mental health and neurological disorders, e) health determinants.

Contribution from health stakeholders is essential to gather:

1. **priorities for action** in each of the above-mentioned strands;
2. **examples of effective policies, best practices, promising approaches**, innovative actions (to be put for consideration of Member States) to effectively address priorities;
3. the **field of work of stakeholders** and actions that stakeholders can do in collaboration with public health authorities and other parties.

Stakeholders may also wish to provide general comments (on the structure of the approach, information gaps, recommendations for better supporting stakeholders, etc.).

How to contribute

You can provide input –or revise and add to your previous input– at any time until the end of the drafting process of the EU NCD Initiative, expected by June 2022.

However, contributions will be particularly appreciated before the webinars, to feed the debate.

When you are ready to do so,

1. Download the document from the Health Policy Platform;
2. Introduce your input; please be concise;
3. Save and send the document to info@euhealthsupport.eu;
4. Revise and resend the document in case you wish to update your input. The previous version will then be replaced.

We may contact member of the Health Policy Platform NCD Stakeholder Group for clarifications. Unless you disagree, responses will be uploaded to the Health Policy Platform and thus readable by other network members. For that reason, please do not include personal information (e.g. names and contact details) in your document.

Calendar

Stakeholders' webinars

- 3 February
- 17 March
- 27 April
- 3 June

Member States' webinars

- 28 January
- 3 March
- 8 April
- 19 May

You will receive a notification when new materials are available at the Health Policy Platform, including summaries and drafts of the EU NCD Initiative and/or new questions for stakeholders.

https://ec.europa.eu/health/non_communicable_diseases/overview_en

Stakeholder input

1. Please provide the **name of the organisation** you represent.
Individual names will not be disclosed; the list of responding organisations may be published.

European Association of Nuclear Medicine (EANM)

2. On which strands of the EU NCD Initiative would you like to comment? Please select all that apply.
 - Health determinants
 - Cardiovascular diseases
 - Diabetes
 - Chronic respiratory diseases
 - Mental health and neurological disorders

You can then fill in the relevant sections below. If you only fill in one section, please add any general comments you may have in the closing section.

Health determinants

1. Please indicate your **priorities for EU-supported action** in this strand.
Please select up to five priorities and be as specific as possible. You may provide a short clarification on why these priorities rank high and add relevant links (e.g. scientific literature, reports of reference institutions, policy documents).

[Note for the Commission's attention: This is a first draft of ECDA suggested priorities – which will be further amended over the coming weeks. An updated/final version will be submitted in May].

	Priorities	Rationale	References
1	<p>Elaborating a European system for data generation and collection on NCDs</p>	<ul style="list-style-type: none"> ● Existing gaps in the availability of relevant and comparable data on NCDs across Europe can be highlighted, as there is currently no centralised scheme for the collection and analysis of NCDs data at the EU level. ● Such gap is a significant barrier to the assessment of the impacts of NCDs for individuals and healthcare systems, it prevents a full assessment of the impact and effectiveness of NCDs policies, programmes and treatments. ● Ultimately, the collection of more data on NCDs will facilitate the understanding of health determinants as key risk factors for NCDs. <p><u>Desirable objective:</u> an EU-wide health data system, including NCD incidence and prevalence/ EU NCDs Registry</p> <ul style="list-style-type: none"> ➤ Identification of gaps in existing data and data collection methods. ➤ Roadmap for how to collect and join datasets/data collections efforts of the various stakeholders and a mapping of organisations/stakeholders who can provide additional support to address identified gaps. ➤ Support to the collection and analysis of data related to NCDs currently missing at the EU level. ➤ Uniformed EU NCD registry (integrated under the European Health Data Space) – pooling together in a coherent and coordinated way NCDs data. 	<p>ECDA, EPHA, NCD Alliance (2019) Towards an EU strategic framework for the prevention of NCDs</p> <p>WHO European NCD dashboard</p>

2. What could be **role of stakeholders** for achieving the priorities, and the actions that the stakeholders can do in collaboration with public health authorities and other parties?

Please list up to five suggestions and be as specific as possible.

You may provide a short clarification on why these suggestions rank high and add relevant links (e.g. scientific literature, reports of reference institutions, policy documents).

	Roles	Rationale	References
1	Healthcare professionals	<ul style="list-style-type: none"> ● Grounding any initiative into the daily clinical practice reality 	
2	Healthcare professional associations	<ul style="list-style-type: none"> ● Bringing expertise and facilitation of consensus ● High attention to good governance 	
3	Patient organisations	<ul style="list-style-type: none"> ● High attention to the meaningful involvement of relevant stakeholders, including citizens 	

Cardiovascular diseases

3. Please indicate your **priorities for EU-supported action** in this strand.

Please select up to five priorities and be as specific as possible.

You may provide a short clarification on why these priorities rank high and add relevant links (e.g. scientific literature, reports of reference institutions, policy documents).

	Priorities	Rationale	References
1	<p>Develop a dedicated European Cardiovascular Plan</p>	<p>Cardiovascular diseases (CVDs), including heart failure, atrial fibrillation-related stroke, heart valve disease or coronary heart disease, can impact people of all ages. CVDs are the leading cause of death in the EU, and an important factor in the numbers of chronic conditions and disabilities. Not only do CVDs have a human health cost, but they also represent a significant financial burden for European healthcare systems. It's time to step up investment in healthcare systems across Europe, and devoting resources to cardiovascular health must be part of this.</p> <p>The European Commission's EU4Health programme, Next Generation Recovery Funds and Horizon Europe Research Funds provide an opportunity to further tackle the burden of CVDs and improve cardiovascular health of citizens. This could be supported by an EU Action Plan on Cardiovascular Diseases.</p> <p>Leveraging Europe's Beating Cancer Plan, this EU Action Plan should consider the complete patient pathway.</p> <p>This could include the following initiatives:</p>	<p>European Alliance for Cardiovascular Health (EACH) – strategic plan: https://www.cardiovascularalliance.eu/</p>

		<ul style="list-style-type: none"> ● Improve data and evidence: Leverage the European Health Data Space to create a common European CVD information system focused on patient outcomes and treatment options, to improve CVD registries and to implement and improve quality measurement indicators to monitor patient access to CVD care. ● Access to diagnosis & treatment: In the framework of the new Public Private Partnership on Health Innovation, facilitate pilots to have efficient access to innovation in a secure manner, such as through Early Feasibility Studies. 	
2	<p>Develop an integrated care approach, considering complications & comorbidities and interactions between NCDs</p>	<p>Recent years have seen increased collaboration and joint work across medical disciplines to establish protocols and care pathways to prevent and manage co-morbidities in NCD patients. However, further work is needed in the area to foster multidisciplinary, integrated care and ensure all patients receive equal access to specialist services across Europe.</p> <ul style="list-style-type: none"> ● Support for early detection/screening of co-morbidities and complications in most vulnerable groups: screening and early detection followed by early action can help tackle disease progression and prevent or delay the onset of disease and life-threatening complications. ● EU support for targeted screening and preventive health checks – focus on at-risk population groups 	

		<ul style="list-style-type: none"> Leveraging existing EU funding programs for research on cancer to include cancer related cardiovascular complications and comorbidities. The aim is to fill existing gaps in research and establish a more holistic understanding of the impact of these conditions. The EU mission on cancer can be the needed infrastructure for such an action in the framework of the EU's Horizon Europe research program, running from 2021-2027. Imaging data acquired as part of patient's care may provide important information on the cardiovascular health status of patients and help identify sub-groups at risk of complications of oncological treatments. The development of image standardization and large European imaging data connected to clinical databases would support risk stratification of patients and early detection of side effects of new oncological treatments. 	
4	Harmonization of cardiovascular imaging data	<p>For diagnostic purposes, Nuclear Medicine procedures require the use of PET/CT scans.</p> <p>Numerous studies have shown significant variations in standard protocols, meaning that the same equipment in different hospitals would not produce the same results for the same patient with the same level of radioactivity. This makes the comparison between results (and patient follow-up) almost impossible between hospitals. This clearly illustrates the need for further standardizing imaging protocols, for continuous training and ongoing standardization in an effort to optimize cardiac PET/CT. Such formalization and</p>	<p>Variations in clinical PET/CT operations: results of an international survey of active PET/CT users: https://pubmed.ncbi.nlm.nih.gov/21233186/</p> <p>Variation of system performance, quality control standards and adherence to international FDG-PET/CT imaging guidelines. A national survey of PET/CT</p>

		<p>quantification require both proper software, proper hardware and equipment and the necessary expertise.</p> <p>In order to develop the necessary software for the standardization of cardiac PET/CT, key learnings from the standardization of oncology PET/CT should be leveraged: what has been done for oncology is a good starting point to develop the necessary solutions for cardiovascular applications.</p>	<p>operations in Austria: https://pubmed.ncbi.nlm.nih.gov/25131649/</p>
5	<p>Supporting proof-of-concepts clinical studies evaluating innovative radiopharmaceuticals in cardiovascular diseases.</p>	<p>Several European SME are currently developing innovative radiopharmaceuticals that have the potential to improve the phenotyping of cardiovascular diseases and support the development of personalized medicine in cardiovascular diseases.</p> <p>To allow promising radiopharmaceuticals to reach the market, financial support to proof-of-concept studies including radiopharmaceuticals for cardiovascular applications taking should be considered. This will support the growth of European SME in radio-pharmacy.</p>	

4. What could be **role of stakeholders** for achieving the priorities, and the actions that the stakeholders can/should lead and can/should do in collaboration with public health authorities?

Please list up to five suggestions and be as specific as possible.

You may provide a short clarification on why these suggestions rank high and add relevant links (e.g. scientific literature, reports of reference institutions, policy documents).

	Roles	Rationale	References
1	Healthcare professionals	<ul style="list-style-type: none"> ● Grounding any initiative into the daily clinical practice reality 	
2	Healthcare professional associations	<ul style="list-style-type: none"> ● Bringing expertise and facilitation of consensus ● High attention to good governance 	
3	Patient organisations	<ul style="list-style-type: none"> ● High attention to the meaningful involvement of relevant stakeholders, including citizens 	
4	Umbrella organizations	<ul style="list-style-type: none"> ● European Society of Cardiology 	

Mental health and neurological disorders

5. Please indicate your **priorities for EU-supported action** in this strand.

Please select up to five priorities and be as specific as possible.

You may provide a short clarification on why these priorities rank high and add relevant links (e.g. scientific literature, reports of reference institutions, policy documents).

	Priorities	Rationale	References

1	<p>Towards a European Brain Initiative & advance synergies</p>	<p>It is time to aggregate thinking, resources, and policy efforts in Europe. And that significant and transformative breakthroughs will come from the best scientists and the innovative work produced so far. This is important to step up efforts at the European level through more strategic funding streams and alignment of research agendas.</p> <ul style="list-style-type: none"> • One step forward could include the establishment of a brain health pillar of the European Health Union and efforts to identify existing and missing funding mechanisms in the Horizon Europe funding program. This would address the risk of fragmentation of funding after the end of some of the large-scale programmes in 2023. • It is also essential to systematically align research agendas across the member states, arriving at a synergetic set of national commitments to the brain health agenda. This will enrich the European Commission efforts and enable rapid development of research and data infrastructures as part of the European brain health landscape. One of the templates for this approach could be the concept of a Knowledge Hub on the Brain to inform policy-makers, modelled after the EC Knowledge Centre on Cancer. • In May 2022 the World Health Assembly (WHA) is expected to adopt the Intersectoral global action plan on epilepsy and other neurological disorders (GAP) which was called for in a 2020 WHA resolution cosponsored by all the EU countries. This is an opportunity to provide an integrated and cross-sectorial response to neurological health. The NCD Initiative actions addressing neurological disorders should fully align with the targets of the GAP which provides a comprehensive framework for national action. This synergistic approach will be the most efficient use of resources that are limited and need to be spent wisely. 	<p>World Health Assembly Intersectoral global action plan on epilepsy and other neurological disorders: https://www.who.int/news/item/28-04-2022-draft-intersectoral-global-action-plan-on-epilepsy-and-other-neurological-disorders-2022-2031</p>
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2	<p>European support for the establishment of national neurological/brain health plans</p>	<p>All neurological disorders share a lot of common denominators, including symptoms and complications, risks and factors, and are all related to the same discipline: neurology.</p> <p>For this specific reason, while specific and dedicated actions are necessary at the clinical level, at the strategic level, all neurological disorders have to be addressed in a joint manner. Experiences attest that such a bundled approach is the most effective way of addressing a disease area.</p> <p>In this respect, successful examples of other overarching national strategies in other research areas, such as cancer should be considered. Europe's Beating Cancer Plan and national Cancer Plans should be considered as a role model of such a bundled approach for neurological disorders.</p> <p>With more than 400 different neurological disorders and the huge collective burden they represent, strategies addressing common challenges and solutions are needed.</p> <p>In line with the recommendations of the GAP (<i>75% of countries to develop a national brain health plan in the next ten years</i>), we believe that the European Union should support Member States in developing such neurological national plans, encompassing all major neurological disorders, distinct from mental health conditions, with a dedicated budget line.</p> <p>Such strategies should constitute integrated, coherent and holistic approaches for tackling the societal challenges associated with brain disorders, enabling national governments to better coordinate brain research and optimize resources at the national level. National plans could then be the basis of further coordination at the European level.</p>	<p>Norwegian Brain Health Strategy: https://www.braincouncil.eu/wp-content/uploads/2019/10/171222-Hjernehelsetilstand-2020-2025-engelsk-utgave-7-3.pdf</p> <p>Brain Plan for Poland: https://www.braincouncil.eu/wp-content/uploads/2019/10/June-2019-folder-BP-po-poprawkach-eng.pdf</p> <p>European Guide for Quality National Cancer Control Programmes: https://cancercontrol.eu/archive/uploads/images/European_Guide_for_Quality_National_Cancer_Control_Programmes_web.pdf</p>
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		<p>For the GAP to be successfully implemented at the national levels, a European platform and guide for high-quality national neurological plans are to be welcomed.</p> <p>To achieve the best results in individual member states, but also at the global level, there needs to be regional coordination. The European Commission is well placed to provide a platform that can facilitate the development and implementation of national plans synergistically. Successful examples exist in other disease areas such as cancer, e.g. European Guide for Quality National Cancer Control Programmes.</p>	
3	<p>Elaborating a European system for the collection and generation of neurological disorders data.</p>	<ul style="list-style-type: none"> Existing gaps in the availability of relevant and comparable data on neurological disorders across Europe can be highlighted, as there is currently no centralised scheme, either at the national or European levels, for the collection and analysis of neurological data at the EU level. Such gap is a significant barrier to the assessment of the impacts of neurological diseases for individuals and healthcare systems, it prevents a full assessment of the impact and effectiveness of brain health policies, programmes and treatments. Reliable data on neurological disorders and their risk factors are the backbone of evidence-based healthcare planning, priority setting and resource allocation. However, these studies are scarce for most neurological disorders, which limits the ability to compare and replicate findings. More high-quality studies of the burden of various neurological disorders are needed. An EU-wide support system for the collection of data on neurological disorders, including incidence and prevalence is to be welcomed. An increase in the capacity of information systems is to be welcomed for efficient measurement 	<p>Routinely collected patient data in neurology research: a systematic mapping review - https://bmcneurol.biomedcentral.com/articles/10.1186/s12883-020-01993-w</p>

		<p>of interventions. Several means can be identified in this respect, including patient registry, or aggregate data.</p> <ul style="list-style-type: none"> • A greater availability and actionability of brain health data is one of the most important cornerstones. This issue strongly applies to brain imaging data including PET and SPECT studies. <p>Efforts should be made to guarantee patients' data protection avoiding too restrictive interpretations of GDPR. Researchers should be able to share data within the EU space (PET and SPECT studies acquired for clinical reasons might be reused to answer research questions)</p> <p>This action is also useful to solve the ongoing reproducibility crisis which also applies to brain imaging. Also, for Brain PET and SPECT is essential to go from the beginning to the end – from acquisition to data processing).</p>	
4	<p>Harmonization of neuroimaging data</p>	<p>For diagnostic purposes, Nuclear Medicine procedures require the use of PET/CT scans.</p> <p>Numerous studies have shown significant variations in standard protocols, meaning that the same equipment in different hospitals would not produce the same results for the same patient with the same level of radioactivity. This makes the comparison between results (and patient follow-up) almost impossible between hospitals.</p> <p>This clearly illustrates the need for further standardizing imaging protocols, for continuous training and ongoing standardization in an effort to optimize PET/CT in neuroimaging. Such formalization and quantification require both proper software, proper equipment and the necessary expertise.</p>	<p>Variations in clinical PET/CT operations: results of an international survey of active PET/CT users: https://pubmed.ncbi.nlm.nih.gov/21233186/</p> <p>Variation of system performance, quality control standards and adherence to international FDG-PET/CT</p>

		In order to develop the necessary software for the standardization of brain PET/CT, key learnings from the standardization of oncology PET/CT should be leveraged: what has been done for oncology is a good starting point to develop the necessary solutions for neuroimaging.	imaging guidelines. A national survey of PET/CT operations in Austria: https://pubmed.ncbi.nlm.nih.gov/25131649/
5	Harmonization of proof-of-concepts studies for Radiopharmaceuticals	<p>Nuclear medicine is a medical specialty that uses radioactive tracers (radiopharmaceuticals) to assess bodily functions and to diagnose and treat disease. In this respect, innovation in Nuclear Medicine lies in the development of new tracers, making diagnosis and treatment easier.</p> <p>However, as these new tracers are often developed in academic centers or clinical settings, for very small groups of patients, this is very complex and burdensome to come with a proof-of-concept in order to prove that a tracer is suitable for clinical practice. This results in a lack of harmonization both at national and European levels, where the same tracers are not used at different sites.</p> <p>To allow promising radiopharmaceuticals to reach the market, further harmonization and support to proof-of concepts studies including radiopharmaceuticals for neuro application taking place in several sites across Europe are to be welcomed.</p>	

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3	Patient organisations	<ul style="list-style-type: none">● High attention to the meaningful involvement of relevant stakeholders, including citizens	
4	Umbrella organizations	<ul style="list-style-type: none">● European Brain Council● EBrains Network	

Please check the boxes that apply:

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- I confirm that the document does not include personal information (e.g. names and contact details)