

European Commission Cancer Inequalities Registry EuroHealthNet's response

EuroHealthNet is a not-for-profit partnership of organisations, agencies and statutory bodies working on public health, disease prevention, promoting health, and reducing inequalities. With a long-term commitment to promoting health equity, we applaud the Commission's efforts to introduce a Cancer Inequalities Registry within its ambitions to address cancer prevalence and incidence, including through effective and evidence-based health promotion and disease prevention solutions, and address the prevailing inequalities that are associated with cancer and co-existing health conditions.

People in disadvantaged groups are predisposed to higher risks of cancers and poorer access to screening, diagnosis, treatment, rehabilitation and care, and the impact of COVID-19 has further worsened such vulnerability. In order to combat this exacerbated situation, efforts must be made to reduce social and economic inequalities in cancer-related health outcomes, increase opportunities for prevention, and minimise the steep social gradients in cancers. We believe this can be done by applying a proportionate universalism approach to preventive and health-enhancing services within primary health care systems. Moreover, it is important to bear in mind that unhealthy and unsustainable lifestyles are often a result of social, economic, and environmental circumstances which accumulate throughout one's life-course. To this end, the approaches taken should not solely tackle individual behaviours (causing a "lifestyle drift" in our actions), but rather, focus on addressing the structural and underlying causes of ill-health and diseases. Improvements in people's living and working conditions such as income and financial protection, housing, air quality, education will all strengthen people's resilience to withstand health and social shocks, be it avoidable and preventable cancers or other non-communicable diseases¹.

In light of the above, EuroHealthNet recommends the following:

1. Addressing the disparities along the socio-economic gradient, within structural settings, and at regional and local level

During the stakeholder webinar organised by the European Commission and the EU Health Policy Platform on the Cancer Inequalities Registry, it was explained that the Registry "*will identify trends, disparities and inequalities between Member States and regions*" with one of the focuses being inequalities across "*vulnerable groups*". Whilst it is important to channel efforts towards vulnerable groups, we also strongly recommend that the Registry captures

¹ Marmot, M. & Bell, R. (2019). Social determinants and non-communicable diseases: time for integrated action. *BMJ* 2019;364:l251 <https://www.bmj.com/content/364/bmj.l251>

the disparities along the socio-economic gradient, accounting for population groups who live in sub-optimal conditions but who are not considered vulnerable (yet, or to definitions in place). Data and evidence on cancer prevention and care services should be able to make a clear link with the underlying living and working conditions at diverse population-groups' level. Moreover, it is crucial that actions stemming from the Registry avoid a “lifestyle drift” and “policy drift” towards individual behaviour change strategies, so as to reflect structural inequalities and subsequently inform on policy processes to address core issues. Lastly, we call for the disaggregation of data at a more granular level, demonstrating the regional and local inequalities in access to cancer prevention and care, in addition to the country-level assessment.

Some of good practice in this regard can be put forward by past Joint Actions and EU-funded projects on cancers, NCDs and chronic diseases more generally, not least by the [CHRODIS+](#) of which EuroHealthNet was part of.

2. Driving investments to finance the delivery of health promoting services that benefit health and wellbeing for all

It was additionally noted that the Registry “*will identify challenges and specific areas of action to guide investment and interventions under Europe’s Beating Cancer Plan*”. In this regard, we believe that the Registry can serve as an important information repository tool to illustrate the importance of *adequate and needs-responsive* financing health promotion and disease prevention services to effectively prevent cancer incidence, morbidity and mortality. EuroHealthNet has developed an [e-guide](#) to provide concrete examples of how investment in health promotion and disease prevention can be mobilised.

3. Linking the Cancer Inequalities Registry to WHO databases and other EU instruments

The Registry should have more consolidated links with WHO databases, the European Pillar of Social Rights and its Social Scoreboard (where a secondary indicator on preventable mortality and morbidity has now been included), the expanded mandate of the European Centre for Disease Prevention and Control and the European Health Union. Moreover, this Registry has the potential to be a fundamental information tool to guide activities supported by EU funding mechanisms, such as the Horizon Europe Mission on Cancer and the Resilience and Recovery Facility.

4. Expanding on the building blocks of the draft indicator framework for the Cancer Inequalities Registry

- a) The *Foundation* block, which aims to also incorporate data on the pandemic impact, should provide information on COVID-19 and cancer prevention, in terms of opportunities for preventative measures missed (and by whom in terms of population

groups along a socio-economic gradient) and the trends of cancer-related risk behaviours and factors. Since the work is underway to expand the ECDC's mandate onto interplay between infectious and non-communicable diseases, specifically in times of pandemics and pandemic preparedness, linking it with data and indicators on cancers will be advised at this stage.

- b) The block on the Beating Cancer Action Plan specifically mentions screening initiatives. However, as with most interventions, its effectiveness vastly interplays with underlying structural determinants of health, and community-driven and needs-linked approaches. To this effect, this block should also integrate data on pre-primary prevention and health promotion measures in a framework of healthy lifestyle and environments (wider Roadmap for targeted NCDs actions relevance, EC's Healthy Lifestyles for All campaign).
- c) The *Policy* block aims to collect information on contextual factors surrounding healthcare, including shortages in workforce and technologies, characteristics of the organisation on cancer care and coverage of cancer registries. Whilst these are important measurables, the policy block should also aim to capture the health promotion, disease prevention and equity lens. As such, information on access to health promotion services, levels of (digital) health literacy skills, the impact of digitisation on managing health also bears contextual importance to policy processes and decision-making.
- d) The *Outcomes* block seeks to include indicators for 5-year survival, length of hospital stay, and patient reported experience and self-reported outcomes. Indicators should be expanded to include the percentage of cancer cases and disability adjusted life years (DALYs) saved and prevented by preventative measures, the return of investment of such measures to prevent cancer, levels of health and digital health literacy, and the progress (or lack thereof) between and within Member States to close the inequalities gap. The outcomes should also reflect on the impact of key initiatives to reduce disparities for cancer survivors upon their return to work, and when trying to access key services such as loans and insurances (as advocated in the "Right to be Forgotten" initiative").

5. Ensuring that information in Cancer Inequalities Registry is accessible to all and understandable for all

As a prospectively important repository on cancer prevention and care, it is essential that the Cancer Inequalities Registry is user friendly for all, and accessible to all. As discussed in the stakeholder webinar, the Registry should be tailored to a wider audience as an information tool. In order to do so, the Registry must be built around the varying levels of digital literacy across different population groups, in order to ensure that unequal access to this tool is significantly mitigated.