

EPF's Response Statement

Public consultation on European Centre for Disease Prevention and Control – reinforced mandate

31 January 2021

The European Patients' Forum welcomes the opportunity to comment on the proposal. Our response focuses on two main aspects.

1. Tackling infectious and chronic diseases at European level

EPF supports the extension of the ECDC's mandate to improve preparedness, surveillance, risk assessment, early warning and response to future cross-border health threats, as well as smooth cooperation between ECDC and other agencies, bearing in mind the likely future creation of centres of excellence and EU disease-specific platforms for exchange and benchmarking of best practices foreseen by the EU4Health programme. We also welcome the proposals to give the ECDC more autonomy to formulate recommendations and actions. However, in recognition of the important and growing health impact of chronic diseases, EPF recommends that the mandate of the ECDC is further extended to encompass chronic diseases.

Timely availability of cross-EU incidence and prevalence data, diagnoses and health outcomes is vital to inform appropriate policy at EU and member state levels. The 2019 evaluation of the ECDC identified the need to strengthen EU collaboration on infectious diseases and suggested the ECDC could respond to the need for comprehensive, evidence-based coverage of population health and burden of disease by providing information on the differences between Member States and related policy needs to improve health, quality of life and well-being. Without EU-level comparable data, the vision of the European Health Union cannot be effectively implemented.

There are already several synergies. Activities that already come into the remit of the ECDC – health education, health literacy, behaviour change – are highly relevant to the prevention of infectious and chronic diseases and health promotion. These activities could be enlarged to address disease prevention, guidelines, recommendations, and programmes addressing health determinants. The ECDC should be also resourced to monitor health systems' capacity with regard to chronic diseases. It has become clear during the COVID-19 pandemic that when a system's capacity is overwhelmed by a communicable disease, it creates a far-reaching detrimental impact on other diseases and can severely harm patients.

2. Engagement with stakeholders and the public

One of the roles of the ECDC is to communicate with the public on communicable diseases, health threats, prevention and control measures among other things. The communication and information capabilities of public institutions are of a growing importance in a society characterised by the instant availability of overwhelming amounts of online information on one hand, and the segmentation of

people into like-minded “bubbles” on the other. This includes unreliable information, misinformation and deliberate disinformation campaigns. The need for readily accessible, evidence-based, trustworthy information based on science and tailored to the needs of lay people is greater than ever, as has been witnessed during the COVID-19 pandemic.

The EMA has had active engagement with patients and consumers since its creation in 1995 – now with a working party for patients and consumers and for healthcare professionals. The ECDC does not have a similar mechanism. The EMA’s experience of early engagement with such stakeholders has been proven to add significant value to its activities, support transparency and improve regulatory processes. Patient and consumer organisations also help to shape information, communication and public messaging to ensure it is optimal, function as effective interlocutors on patient concerns, and as dissemination hubs to their communities.

We believe the addition of a permanent, sustainable stakeholder engagement platform similar to that of the EMA, and other agencies like EFSA and ECHA, would enhance the ECDC’s public engagement, add to its credibility and help raise public awareness of ECDC as an expert body and a reference point for trustworthy information.
