Webinar Report

"Data-Informed Health Policy"

Date: November 6th, 2024

Location: Virtual

Recording available: https://epha.org/events/data-informed-health-policy/

Organized by: European Public Health Alliance (EPHA)

Overview

The "Data-Informed Health Policy" webinar focused on the critical role of data in shaping effective public health policy and the various tools and methodologies that can be used to collect, assess, and apply health data across Europe. Speakers from various organizations discussed how Health Information Systems (HIS), stakeholder collaboration, and responsible data use can improve healthcare outcomes, particularly during crises like the COVID-19 pandemic. The event brought together experts from public health institutions, research organizations, and NGOs to explore how health data can be used to enhance policy decisions and improve patient outcomes.

Key Takeaways from Presentations

Miriam Saso – Project Manager and Researcher, Sciensano

Miriam emphasized the importance of building robust Health Information Systems (HIS) to support public health action across Europe. She outlined that a health system begins with data collection, which evolves into information, then knowledge, and ultimately wisdom—the application of knowledge to improve health outcomes.

The current state of public health information systems is evaluated through comprehensive assessments, which are conducted to identify strengths and weaknesses that can inform innovations for system improvements. A multi-step process is employed in these assessments: desk reviews, stakeholder selection, country visits, and debriefing meetings. The goal is to ensure that stakeholders collaborate and transfer information effectively to inform health policy. In this sense, Miriam is currently involved in the EU Health Information Platform (EU-HIP) and initiatives like TEHDAS and PHIRI, which aim to improve the willingness and preparedness of countries to join collaborative health data-sharing efforts.

Milana Trucl – Policy Officer, European Patients' Forum

Milana introduced the "*Data Saves Lives*" initiative, which seeks to harness the power of health data while ensuring responsible and ethical use. The initiative includes multi-stakeholder bootcamps designed to bridge the knowledge gap on data use, focusing on health data technology, EU legislation, and patient literacy.

Bootcamps cover topics like artificial intelligence in healthcare, the role of disease registries, and how patient organizations can utilize health data to improve outcomes. A key principle is that there can be no responsible use of data without patient literacy. Thus, the initiative creates toolkits after each bootcamp to empower organizations to better understand and use health data. The toolkits are translated into local languages and customized to local contexts, making them accessible to a wide range of stakeholders.

Laura Berthoud – Researcher in Equality Data, Unia

Laura discussed the role of her organization in promoting equality and non-discrimination, particularly within the context of healthcare access for marginalized populations, such as Roma and Travellers.

UNIA has developed a platform for collecting data related to health inequalities, which can then be used to influence policy decisions. The platform helps gather data on specific groups, such as ethnic origin and disability, and makes it easier for policymakers to identify gaps in healthcare access. Data-driven policy is crucial, but the challenge lies in making sure the data is comprehensive and reflects the real needs of vulnerable populations. There is a significant focus on the intersectionality of race, disability, and ethnicity, and how these factors influence access to healthcare.

Inés Nieto – Professor, Research Centre in Sport Science, King Juan Carlos University

Inés introduced the Social Return on Investment (SROI) model, a framework for measuring the social impact of health policies and programs. SROI provides a structured approach to assess how investments in health initiatives translate into measurable outcomes for various stakeholders.

The SROI model is a six-step process that includes identifying stakeholders, defining the theory of change, and quantifying outputs and outcomes. This model is used to measure the social value of public health investments. A case study on the *Gloucestershire Active Together Program* demonstrated how to apply the SROI framework, emphasizing the importance of developing a theory of change and using measurable indicators. While the SROI model is globally applicable, Inés highlighted the need for local adaptation to ensure it aligns with regional contexts and cultures.

Maria Claudia Badino – Team Leader for Digital Innovation Policy, European Commission

Maria Claudia Badino discussed the Big Data Test Infrastructure (BDTI), an initiative designed to support EU public administrations in making better use of data for policy and decision-making. BDTI provides free open – source tools for data collection, processing, analysis, visualization, decision-making.

BDTI is designed not just for big data but for all types of public sector data, helping to assess data quality and create a feedback loop to improve data driven decision-making. BDTI is ~~partially~~ funded ~~under the AI, Cloud, and Data Pillar of~~ by the Digital Europe Programme (DEP), and is available for free for EU public administrations ~~for up to six months~~. The infrastructure is EU-wide ~~and available in all 24 EU official languages~~, promoting data-driven policy and the responsible use of data with the objective to create a single European market for data sharing.

Conclusion

The webinar underscored the critical role of health data in shaping effective public health policies. As data becomes increasingly central to decision-making, it is essential that health information systems are strengthened, data is shared responsibly, and stakeholder collaboration is prioritized. This can help ensure that health policies are equitable, evidence-based, and responsive to the needs of diverse populations across Europe.

The discussions highlighted the potential for data-driven approaches to improve healthcare outcomes while addressing the ethical and legal challenges surrounding data use in the public sector. Moving forward, it is essential to foster an environment where data literacy and stakeholder collaboration are central to creating a more inclusive and effective health policy landscape.