World Health Organization
REGIONAL OFFICE FOR Europe

The European Region Health Information Network

Terms of Reference

1. Background

The coronavirus disease (COVID-19) pandemic has clearly shown the importance of health data governance and well-functioning health information systems (HIS) that produce robust, timely and policy-relevant health intelligence. It has, however, also put a spotlight on existing problems and malfunctions in HIS. Common HIS challenges include limited resources and capacity; insufficient coordination and collaboration between HIS stakeholders, leading to fragmentation and problems with interoperability; a lack of central governance; and limited use of health information for decision-making. Both at the level of the WHO Regional Office for Europe and the European Commission, policies and strategies are being implemented to support Member States in strengthening their HIS, thereby improving the availability of high quality, timely data for evidence-informed decision-making, both at country, and European Union (EU) and WHO European Region levels. Supporting the further digitalization of HIS is an important element in this.

A major current development at the EU level is the development of the European Health Data Space (EHDS). The EHDS provides a regulatory framework that directly addresses the rights of individuals reduces fragmentation in the digital single market and enables researchers, innovators and policy-makers to more effectively use the data securely, building on strong data protection and cybersecurity elements *(1)*. The 2018 *Communication on enabling the digital transformation of health and care in the Digital Single Market; empowering citizens and building a healthier society* aims to promote health, prevent and control disease, help address patients' unmet needs and make it easier for citizens to have equal access to high quality care through the meaningful use of digital innovations *(2)*. In addition, the 2022 *EU Global Health Strategy* focuses on achieving health systems that are effective, resilient and accessible in all their fundamental aspects, including HIS, as well as on fostering digitalization as a fundamental enabler *(3)*.

Supporting Member States in strengthening their national HIS to improve evidence-informed decision-making is a priority area of WHO's work under the *European Programme of Work 2020–2025 – "United Action for Better Health in Europe"* (EPW) *(4)*. Over the past years, WHO has substantially expanded its tools and guidance to assist countries in strengthening HIS and boosting the use of health data. These tools serve three main purposes: operationalizing the measurement framework for the EPW *(5)*; enhancing country capacities to establish, enhance and evaluate integrated and effective HIS; and using digital data sources and big data

to leverage the predictive power of data to improve the health and well-being of all in the WHO European Region (see chapter 4 of the *European Health Report 2021 (6)* for more information on WHO's HIS strengthening tools). The EPW Flagship initiative Empowerment through Digital Health *(7)*, the *WHO Global Strategy on Digital Health 2020–2025 (8)*, and the *Regional digital health action plan for the WHO European Region 2023–2030 (9)* all intend to support countries in leveraging and scaling up digital transformation for better health and in aligning digital technology investment decisions with their health system needs, while fully respecting the values of equity, solidarity and human rights.

Within this context, the European Commission has requested that the WHO Regional Office for Europe implement the action *Partnering with the EU to strengthen health information systems, data governance and interoperability in Europe (10)*. This includes HIS strengthening through promoting, where possible, the principles and solutions included in the proposed legislation for the EHDS. The action will also contribute to the objectives of the new EU Global Health Strategy to improve global health security and deliver better health for all in a changing world.

One of the specific objectives of the action is the creation of a multi-member Health Information Network (HIN) for strategic engagement to support the priority setting for activities within the scope of the action and to stimulate exchange. The HIN will build on the work done by other WHO Regional Office for Europe networks in the field of health information, most notably the European Health Information Initiative (EHII) and the EPW Measurement Framework Working Group. Therefore, the HIN can be seen as a restart of these initiatives, refocusing its priorities, activities and working methods to align with current issues and developments.

2. Vision, mission and expected outputs

The vision of the HIN is better health of the people of the European Region through improved evidence-informed policies.

The mission of the HIN is to foster international cooperation in order to exchange expertise, build capacity and harmonize data collection and statistics generation to improve data and health information for policy-making.

The expected outputs of the HIN are:

a) enhanced international coordination and cooperation for the benefit of participating countries through the platform created and engagement activities conducted;
b) the facilitation of knowledge exchange at the Regional and global levels by sharing national good practices and learning from others to facilitate Regional, national and local progress;
c) strengthened structures are in place in participating countries to facilitate coordination and to work towards strengthening HIS and shared health data governance and interoperability practices; and
d) the development and adoption by the HIN of a workplan to strengthen HIS, health data governance, data quality and interoperability in the participating countries.

3. HIN key functions and guiding principles

The HIN will support the development of a work plan for the EU-funded action and will identify areas for mutual discussion and interregional collaboration, and define recommendations for strengthening HIS and boosting health data governance and interoperability in the WHO European Region. The network will improve the quality of health information through fostering international cooperation and facilitating knowledge exchange between participating countries in order to build capacity and harmonize data collection and statistics generation. The network will seek, when possible, through its recommendations, the alignment of policies and information systems with those present in the EU, e.g., the EHDS and the EU Global Health Strategy.

The HIN's work will be based on the following guiding principles:

- The HIN will take into account earlier and parallel work done in the field of health information to prevent overlaps and stimulate synergies by:
    - building on the work done by the EHII and the EPW Measurement Framework Working Group;
    - serving as complementary entity to the EU eHealth Network and its respective subgroups and the future EHDS Board included in the EHDS legislative proposal;
    - including in the network representatives of existing health information or health information-related subregional networks such as the Central Asian Republics Information Network, and the Small Countries Health Information Network, the South-eastern Europe Health Network.
- The HIN strives for representation from all 53 European Region Member States in the network.
- The HIN in its work will maintain compatibility with and contribute to existing monitoring frameworks, at both global and Regional level, most notably the Sustainable Development Goals, the indicators of the EPW Measurement Framework, the WHO Health for All database, and the European Core Health Indicators.
- The HIN aims to contribute to reducing inequalities both within and between Member States, particularly in the aftermath of the COVID-19 pandemic.
- The HIN aims to enhance interagency collaboration.
- The HIN aims to enhance intersectoral collaboration.

4. Composition and membership of the HIN

a) The HIN network is comprised of WHO European Region Member State representatives with expertise in health information; international organizations including the European Commission (the Directorate-General for Health and Food Safety, Eurostat, and other Directorate-Generals when relevant/desirable) and the Organization for Economic Co-operation and Development; and WHO Collaborating Centres.

b) Network membership will be assessed by WHO in its sole and absolute discretion, and in accordance with WHO rules and regulations, policies and practices.

c) The Chairperson of the network will be elected from among the members of the HIN. The Chairperson will serve for an initial period of two years. There will be the

possibility of renewal for a further period of 2 years through re-election. He/she will chair the bi-annual HIN meetings and potential additional ad hoc meetings (see Section 5. Modus operandi, point b) and prepare these meetings together with the WHO Secretariat (in close collaboration with the European Commission), and represent the HIN in different meetings related to health information, if required.

d) A Vice Chairperson will be elected by the HIN members and will serve for the same period as the Chairperson. He/she will assist the Chairperson in his/her duties, as required.

e) The HIN network is not a legal entity and cannot therefore undertake any action without the explicit agreement in writing of each participating organization, agency and institution or individual.

f) Any member may terminate its involvement in the HIN by providing written notice to WHO in its capacity as provider of Secretariat services to the HIN. In addition, WHO, in its sole discretion, may terminate the participation in the HIN of any member.

5. Modus operandi

a) Subject to the availability of sufficient human and financial resources for this purpose, the Secretariat will be provided by WHO, acting through the Data and Digital Health unit of the Division of Country Health Policies and Systems at the European Regional Office. HIN related communication is facilitated by the Secretariat hosted by the Regional Office.

b) Meetings of the HIN will be held bi-annually, with one in-person and one virtual meeting each year, pending agreement with the network members. Additional meetings may be convened as required by the Secretariat in consultation with the members. Email exchanges and videoconferences may be used for communication on a regular basis.

c) For the bi-annual HIN meetings, meeting reports shall be produced. For that purpose, a rapporteur shall be selected for each meeting at the beginning of the meeting. Reports on HIN meetings shall be submitted to the Country Health Policies and Systems Divisional Director and made available at WHO's public website.

d) HIN topic-specific working groups shall be established, whose tasks will be to address, in depth, a key area of activity in line with the priorities set by the HIN in the workplan (see Section 2. Vision, mission and expected outputs), e.g., quality of health information, international collaboration, defining recommendations for HIS strengthening or health data governance. Modus operandi for the working groups shall be determined in more detail by the HIN during its first meeting.

e) All meetings will include simultaneous interpretation in English and Russian, and meetings materials (i.e., presentations and important documents necessary to review and share prior to meetings) and meeting reports will be made available both in English and Russian.

f) Members of the HIN should be free of actual, potential or apparent conflict of interest. To this end, proposed members will be required to complete a declaration of interest form on an annual basis, and their appointment will be subject to the evaluation of completed forms by the Secretariat, determining that their participation would not give rise to a real or perceived conflict of interest.

g) The work of HIN members will be pro bono.

h) Consultants for specific topics to be addressed at HIN meetings may be invited by the Secretariat, if deemed appropriate, as observers. Furthermore, the participation of representatives of other WHO entities and/or special institutions will be considered in accordance with the agenda of the corresponding meeting and the institution's area of expertise, and according to the needs expressed and defined by the HIN.

i) The HIN will be active during the *Partnering with the EU to strengthen health information systems, data governance and interoperability in Europe* action funded by the EU *(10)*, which runs for 48 months as of 1 August 2023. After that, continuation of the HIN will be considered by the Regional Director based on Member States' needs and available resources at that time.

6. Publications

a) As a general rule and subject to its discretion, WHO shall be responsible for issuing publications about the HIN activities. All decisions about the preparation and dissemination of publications made by HIN members (other than WHO) concerning HIN activities shall be made by consensus. For the avoidance of doubt, dissemination of HIN materials will only be made by WHO or as may be decided by WHO on a case-by-case basis.

b) Copyright in any publication made by WHO shall be vested in WHO. This also applies if the work is issued by WHO and is a compilation of works by HIN members or is otherwise work prepared with input from one or more HIN members. Copyright in a specific separable work prepared by a HIN member shall remain vested in that member (or remain in the public domain, if applicable), even if it forms part of another work that is published by WHO and of which WHO owns the copyright as a whole.

c) "Publications" include any form, whether paper or electronic, and in any manner. Parties are always allowed to cite or refer to HIN publications, except for purpose of promoting any commercial products, services or entities.

d) Any publication about HIN activities issued by an HIN member other than WHO shall contain appropriate disclaimers as decided by WHO, including that the content does not necessarily reflect the views or stated policy of the participating organizations, agencies and institutions (including WHO, acting as the Secretariat for the network, and the European Commission, as main funder of the action).

e) WHO shall be vested with a non-exclusive, worldwide, royalty-free and sub-licensable license to use, reproduce, synthesize, adapt, publish and disseminate in whatever format – paper, electronic or otherwise – and in whatever manner as WHO may deem appropriate for public health purposes, the work produced by each HIN member *within the context and work of the HIN*.

7. Liability

Under no circumstances shall WHO assume any liability for acts carried out by HIN members regardless of whether such acts were carried out in the name of the HIN. Furthermore, WHO in its sole discretion, may refrain from implementing any decision of the HIN if in the view of

WHO, such decision gives rise to undue financial, legal or reputational liability or is contrary to WHO rules, regulations, administrative practices and programmatic and technical policies.

8. WHO name and emblem

Without the prior consent of WHO, no member shall, in any statement or material of an advertising or promotional nature, refer to its relationship with WHO or use the name and emblem of WHO.

9. Amendments

These Terms of Reference may be amended by WHO, in close cooperation with the European Commission, and all HIN members shall be informed of such changes and shall be required to endorse them as a condition for their continuous participation in the network.

10. References[1]

1. European Health Data Space. In: European Commission [website]. Brussels: European Commission; 2023 (https://health.ec.europa.eu/ehealth-digital-health-and-care/european-health-data-space_en).

2. Communication on enabling the digital transformation of health and care in the Digital Single Market; empowering citizens and building a healthier society. Brussels: European Commission; 2018 (https://digital-strategy.ec.europa.eu/en/library/communication-enabling-digital-transformation-health-and-care-digital-single-market-empowering).

3. EU Global Health Strategy: Better Health for All in a Changing World. Brussels: European Commission; 2022 (https://health.ec.europa.eu/publications/eu-global-health-strategy-better-health-all-changing-world_en).

4. European Programme of Work. In: WHO Regional Office for Europe [website]. Copenhagen: WHO Regional Office for Europe; 2023 (https://www.who.int/europe/about-us/our-work/european-programme-of-work).

5. Seventy-first Regional Committee for Europe: virtual session, 13–15 September 2021: measurement framework for the European Programme of Work, 2020–2025: approach, targets, indicators, and milestones. Copenhagen: WHO Regional Office for Europe; 2021 (https://iris.who.int/handle/10665/343314).

6. The European Health Report 2021. Taking stock of the health-related Sustainable Development Goals in the COVID-19 era with a focus on leaving no one behind. Copenhagen: WHO Regional Office for Europe; 2022 (https://iris.who.int/handle/10665/352137).

7. Empowerment through Digital Health. In: WHO Regional Office for Europe [website]. Copenhagen: WHO Regional Office for Europe; 2023 (https://www.who.int/europe/initiatives/empowerment-through-digital-health).

8. WHO Global Strategy on Digital Health 2020–2025. Geneva: World Health Organization; 2021 (https://www.who.int/publications/i/item/9789240020924).

9. Seventy-second Regional Committee for Europe: Tel Aviv, 12–14 September 2022: Regional digital health action plan for the WHO European Region 2023–2030. Copenhagen: WHO Regional Office for Europe; 2022 (https://iris.who.int/handle/10665/360950).

10. Partnering with the EU to strengthen health information systems, data governance and interoperability in Europe action. In: WHO Regional Office for Europe [website]. Copenhagen: WHO Regional Office for Europe; 2023 (https://www.who.int/europe/activities/partnering-with-the-eu-to-strengthen-health-information-systems--data-governance-and-interoperability-in-europe).

[1] All online weblinks were accessed on the 4 January 2024.