04

New frontiers in health information and evidence

Key messages

Some of the main problems with data collections used to inform the Health 2020 monitoring framework relate to data quality, regularity of collection and timeliness of reporting. Improvements in certification and coding practices will significantly strengthen the quality of cause-of-death data. Compliance by all Member States with the recommended level of detail of reporting to WHO would further increase the utility and comparability of indicators based on these data.

WHO and many countries have experienced a paradigm shift in public health from focusing on death and disease to focusing on health and well-being. More weight should be given in health information to subjective and qualitative data to ensure that it reflects this shift.

Exploring non-traditional sources of health information should be considered to improve reporting on health and well-being across the European Region. Historical records and anthropological observations may be useful sources of information on well-being. Data sources such as social media, mobile phone data and electronic health records can add new insights to regular health statistics.

Health 2020 monitoring should be optimized by looking beyond the usual indicators and broadening its scope to include concepts such as community resilience, empowerment and sense of belonging.

Broad international cooperation is required to tackle current health information challenges efficiently and sustainably. Countries should drive the priority-setting for such international research and development activities.

The European Health Information Initiative is a WHO network of stakeholders, including Member States, committed to enhancing health in the Region by improving the information that underpins policy. It supports the development of a single European health information system, as outlined in the Joint Declaration (126) adopted by the WHO Regional Office for Europe and the European Commission in 2010.

Introduction

WHO is responsible for providing leadership on global health matters, shaping the health-research agenda, setting norms and standards, articulating evidence-informed policy options, providing technical support to countries and monitoring and assessing health trends *(127)*. Thus, monitoring health is an explicit part of WHO's mandate, and the Organization has always had a strong focus on improving, collecting and disseminating health information. On closer examination, however, WHO has so far clearly focused on monitoring not health but death and disease and their determinants, as have other health information stakeholders. The focus on mortality and morbidity was the prevailing public health paradigm, but this is now shifting. The European Region is faced with an ageing population and will have to deal with rising prevalence of chronic diseases and comorbidity, meaning that questions related to issues such as self-reliance, disease management, quality of life, well-being and their determinants are becoming more pressing.

The shift in focus in public health is not only a consequence of an ageing population. The way health is conceived has changed considerably over the last few decades: it is now seen as an

element in a complex interplay of broad societal aspects, rather than an isolated outcome of "narrow" health policies. For example, it is increasingly acknowledged that improving health requires comprehensive policy action, focusing on improving not only health per se but also the broader determinants of health. The monitoring framework for Health 2020 reflects these current views on health by incorporating explicit targets and indicators on well-being and inequities in health associated with social determinants. Other initiatives have also emphasized the need for such a focus; for example, recommendation 4(c) of the European review of social determinants and the health divide is: "undertake regular reporting and public scrutiny of inequities in health and its social determinants at all governance levels, including transnational, country and local" *(128)*.

While the paradigm shift in how health is viewed is now well established, the subsequent shift in focus in population health monitoring still lags behind. Developing solid indicators and identifying suitable data sources for new concepts such as well-being is methodologically challenging: such processes require time, especially because of the need to focus on subjective measures and qualitative data – these issues are not entirely familiar in regular health monitoring and give rise to a number of challenges. Health 2020 also contains other concepts that have not previously been measured routinely, such as community resilience and empowerment – substantial development work is required to operationalize these for monitoring purposes. Quantifying these concepts and measuring their development over time are important for a comprehensive understanding of the success of Health 2020 implementation.

Operationalizing new concepts for monitoring is not something that can be done quickly, and incorporating conceptual changes into population monitoring will take time. Nevertheless, while describing the progress towards the Health 2020 targets in this report it became clear that there is also room for improvement in existing data collections monitoring the standard indicators, such as those on mortality and risk factors. This chapter addresses these challenges and areas for future work, both in the context of Health 2020 and beyond, making links with existing work and initiatives by WHO and other health information stakeholders.

Monitoring the Health 2020 indicators on mortality and risk factors

Timeliness of reporting

Chapter 2 looked at the progress made towards the Health 2020 targets using 2010 data as a baseline. One of the main findings was that only a limited number of countries have yet reported data for several of the core indicators. For example, the average premature mortality rate for 2011 is based on data from 35 countries and the rate for 2012 on data from 28. At the time of writing only one country had reported 2013 mortality figures to WHO. These figures reflect a considerable delay between data collection and reporting.

This has a knock-on effect on the comprehensiveness of WHO databases and the robustness of regional averages. WHO is working with countries to improve timeliness of reporting; timely information is important not only for mortality rates but also for a wide range of other data, including those on infectious diseases and their incidence.

Data quality and availability

In addition to concerns over the timeliness of reporting of mortality data, quality issues are also evident. These include the appropriate use of coding for causes of death and the need to provide adequate levels of detail. Not all countries report mortality data to WHO according to the required three- or four-character ICD-10 coding. Two countries use the ninth and not the most recent (tenth) revision of ICD to report causes of death; others have implemented ICD-10 but fail to report the data with an adequate level of detail, which limits analytical possibilities. Further, in many countries substantial proportions of medically certified deaths are assigned to either ill-defined (ICD-10 codes from chapter XVIII) or nonspecific codes, which have little or no public health meaning. WHO is also working with countries to improve data quality. More information about quality issues related to mortality data is provided in Annex 1.

Another data availability problem identified in Chapter 2 relates to countries' reporting of risk factors, including tobacco use, alcohol consumption and overweight/obesity. This report uses WHO estimates for these indicators as data are scarce in the European Health for All database. This probably results from delays in country reporting to WHO, as well as a lack of availability of regular data at the national level. Although estimates in themselves are a valuable source of information, such data are usually calculated for one or a few time points and cannot therefore be used to monitor longer-term time trends. Solid and timely trend data are needed for a longer-term policy such as Health 2020 so that its impact can be monitored. This is especially true for risk factors: risk factor data show the quickest response to policies and change long before changes in mortality, for instance, can be detected. National health information strategies should therefore encompass regular health interview surveys, and health information systems should be equipped to perform these and analyse their results.

Monitoring health inequities

Monitoring of health inequities encompasses two kinds of activity. The first is the calculation of overarching health inequity indicators, such as income distribution or the percentage of the population not educated at secondary school. The other is the disaggregation of indicators on mortality, morbidity, risk factors and so on. Such indicators are broken down into smaller components using inequity stratifiers such as age, sex, education level and income. Geographical stratification of data can also be useful in assessing health inequities.[3]

This dual approach – using both overarching and disaggregated indicators – is applied to monitoring progress towards the Health 2020 target to reduce health inequities related to social determinants in the Region. Disaggregated data are scarce, however, at the international level.

[3] See, for example, the WHO equity in health atlases (129).

Disaggregated data and linking of data sources

The lack of disaggregated data in international databases for monitoring health inequities is problematic, but obtaining such data is quite demanding. For example, problems exist with the frequency and regularity of national health interviews. These contain information on health and background variables for each respondent, and as such are an important source for disaggregated indicators.

In addition to self-reported data, other information – such as hospital or primary care data – should be disaggregated to ensure comprehensive monitoring of health inequities. This requires linking the data sources at the individual level with other sources containing the necessary background variables for disaggregation. Much work is required if national health information systems are to achieve this. A unique, broadly applied personal identification number should be used for preference, allowing for easy linkage across data sources. If this is not feasible, other identifiers – such as date of birth or postcode – could be used to link information held in different databases. This requires systematic collection of identifiers with high levels of coverage.

A workable legal framework should be in place alongside these technical requirements. Public health experts have stressed that the current revision of the relevant EU legislation could seriously jeopardize the ability to link large data sets for population health monitoring at the individual level. Concerns were raised in response to amendments adopted by the European Parliament to the first Commission proposal for a new EU general data protection regulation *(130)*. The revision process continues and a final decision was pending at the time of writing.

Countries can learn much from each other by sharing good data linkage practices. In particular the Nordic countries, with their long history of registry-based research, can be an important source of knowledge. A recent HEN synthesis report recommended further international exchange about best practices, related not only to data linkage but also to aspects of the broader integration of health information systems, such as the integration of data and information across policy domains at the national level *(131)*.

The expert group advising on the indicators for the Health 2020 targets recommended that, whenever available, indicator data should be disaggregated by ethnicity and vulnerable groups *(132)*. Gathering and monitoring health data for specific groups usually outside the scope of health systems, such as undocumented migrants, is very challenging; such data are not yet part of regular international data collections. The WHO Regional Office for Europe Public Health Aspects of Migration in Europe project contributes to filling the current information gap by collecting health data on migrant populations. For instance, it is collaborating with Italian partners to monitor data on health behaviours in the resident migrant health population in Italy *(133)*. Box 3.2 gives an example of how narrative sources of data can be used to enable migrant populations to articulate their well-being.

Innovative solutions should be put in place to reach and monitor population groups in vulnerable situations. In this respect, close collaboration with other sectors (such as social affairs), non-state actors and different government levels (such as local authorities) is needed, given their greater proximity to migrant populations.

Monitoring well-being

The definition of well-being used by WHO has both objective and subjective dimensions, as described in Chapter 3. Each presents challenges. Collecting data on objective well-being raises the issues and problems outlined earlier in this chapter in relation to other objective indicators. Measuring subjective well-being, on the other hand, presents different challenges, some of which were also described in Chapter 3. Chief among these is that the current Health 2020 monitoring framework only includes one subjective well-being indicator (life satisfaction). This indicator is a starting point to describe a very complex and rich topic. It is not part of regular WHO data collection, which means that WHO is dependent on obtaining information from a third party.

One important way to improve subjective well-being monitoring would be to investigate other forms of evidence from a wider array of disciplinary perspectives. A great deal of rich health information can be gathered about the well-being of groups,

communities and even nations by systematically analysing historical records, anthropological observations or other forms of cultural output.

Monitoring the broader impact and success of Health 2020

As outlined in Chapter 1, to monitor the implementation of the Health 2020 policy and its impact a framework was developed that includes targets and indicators (see Annex 1 for more details). The indicators represent commonly applied measurements such as premature mortality, life expectancy and lifestyle factors including tobacco use. Crucial to Health 2020, however, is its innovative approach, which incorporates the many recent societal changes in the Region that have given rise to the reframing of concepts of and approaches to health described earlier. Consequently, Health 2020 contains many concepts – or outcome measures – that have not previously been measured routinely, such as:

- transparency
- community resilience
- supportive environments
- enabling environments
- sense of belonging
- sense of control
- whole-of-society approach
- participatory governance
- responsible governance
- accountability
- life-course approach
- empowerment
- people-centred health systems
- fit-for-purpose health systems
- adaptive policies.

Painting a full picture of Health 2020 implementation and its impact requires looking beyond the usual indicators and broadening the scope of monitoring. Future challenges include

measuring whether communities in the European Region are resilient or how the sense of belonging experienced by populations in Europe changes over time.

Defining concepts

An inventory needs to be assembled of new concepts, including existing definitions and concepts that remain unclear – at a minimum for qualitative reporting purposes but where possible also for quantitative measurement. This requires the involvement of experts from numerous disciplines, who should also discuss the centrality of each concept to implementation success; this may lead to prioritizations within the list. All concepts may not be equally important and they are certainly not equally measurable.

Comprehensive mapping of all the relevant work related to defining and measuring these concepts will be an important first step. Some is carried out by other agencies, such as the work on resilient communities by the RAND Corporation *(134)*. Other concepts, such as "accountability", are partially measured through the WHO Regional Office for Europe survey on Health 2020 in the context of target 6 (see Box 2.6). WHO is also engaged in work on operationalizing empowerment *(135)*, and is embarking on further implementation of the life-course approach in the context of Health 2020: in October 2015 a European ministerial conference will be held in Belarus to address questions such as the following.

- What exactly is meant by a life-course approach?
- What goals does this approach aim to achieve?
- Which interventions can be used to achieve these goals?
- How can the process and outcome be measured and monitored?

Despite these open questions, a stronger focus on a life-course approach will clearly require more and better data disaggregated by all age groups of the population and by sex; these areas need to be strengthened in both national and international health information systems.

Following this, suitable indicators or qualitative measures that are both meaningful in a Health 2020 context and applicable at the regional level need to be defined and data sources identified

to fill them. The current work on the development of well-being measures described in Chapter 3 clearly shows that this is not a trivial task. Where existing data are not available, discussion of further data collections may be necessary. Instead of overburdening countries with multiple new data collections, relevant types of existing evidence need to be identified that facilitate the assessment of implementation. This would include previously uncharted territory from other disciplines, including qualitative measures and narrative research approaches, which need to be appraised for their suitability. Such work needs to be conducted for all concepts outlined in Health 2020 that have not previously been measured routinely. The results will be better descriptions and potential quantifications of these concepts and further understanding of how they interrelate and the effects of these interrelationships. The Regional Office is developing a proposal for Member States on a mechanism and roadmap to monitor all concepts enshrined in the Health 2020 policy.

Monitoring beyond Health 2020

Health 2020 is the overarching health policy for the European Region. As such, its monitoring framework takes a central place in both WHO's health information activities and those of many countries. Nevertheless, a broader and more detailed scope is needed to ensure comprehensive public health monitoring. The Health 2020 indicators should be viewed as a core set of markers to be combined with other indicators for topics not covered by the monitoring framework. Equally, more detailed indicators for certain topics can help to provide an understanding of situations in individual countries. In addition, monitoring frameworks are not static: indicators on emerging diseases or newly detected risk factors, for example, may need to be added to existing indicator sets. When working to ensure the best evidence-informed policy, health reporting and knowledge translation are essential aspects of monitoring, alongside data collection and analysis. Various areas for development in health information can be identified for monitoring beyond Health 2020; some of the most relevant and urgent are addressed below.

Disease prevalence and incidence data

The lack of comparable data on chronic disease prevalence and incidence at the international level is a well known issue; it is the main reason for the absence of morbidity indicators in the Health 2020 framework. Calculating solid incidence and prevalence figures at the national level is challenging as it generally requires modelling efforts and the linkage of different data sources. Regular and reliable country incidence and prevalence figures are therefore scarce, and those available are often unable to be compared as they reflect differences at the national level in health care organization and availability and usability of data sources.

Biomarkers and data on burden of disease

Two other important health information areas that require further developmental work, and that are linked to the need for comparable incidence and prevalence data described above, are data on biomarkers and burden of disease.

Biomarker data are gained from objectively measured biological parameters following health examinations. An example would be data on glycated haemoglobin taken from blood samples to infer the prevalence of diabetes mellitus in the general population. While routine administrative sources or health interview surveys can be used to look at the prevalence of diagnosed cases, population-representative blood samples can determine the prevalence of cases not diagnosed.

Burden-of-disease studies provide valuable public health insights that cannot be gained from assessment of single sources of mortality or morbidity data alone. They entail the calculation of disability-adjusted life-years, which combine years of life lost due to premature mortality and years lived with disability. This enables the burden of ill health across diseases and risk factors to be compared at different time points and locations. Carrying out such a study is challenging, however, and calculating burden-of-disease measures requires extensive data and specific expertise. The experiences of several countries now developing their own burden-of-disease studies may help to inform the generalized application of such studies throughout the Region.

The WHO Regional Office for Europe supports countries in this regard by working closely with the Institute of Health Metrics and Evaluation in Seattle, United States of America, facilitating capacity-building activities, reviewing the data sources and results obtained and promoting the use of such results for policy-informed decision-making.

Health reporting and knowledge translation

Health monitoring is not only the analysis of data and indicators; ensuring that health information is used effectively in the policy-making process is equally important. The way health information is reported is a significant element in this, including the process of content creation, writing style and design. Although consensus is growing on what constitutes effective health reporting, a sound centralized evidence base is still frequently lacking. To overcome this, much could be gained if country experiences were shared more systematically and widely. For example, Sweden has achieved a very successful subnational reporting cycle on health care quality, which has resulted in rapid, effective policy responses (see Box 4.1).

In the field of knowledge translation, significant capacity remains for establishing sustainable mechanisms in countries to increase the systematic use of health-research evidence in policy-making (see the information on the Evidence-informed Policy Network later in this chapter).

Forecasting

Forecasting or foresight exercises require multiple data sources, integrative models and qualitative scenarios based on discussions with policy-makers, members of the public and other stakeholders, as well as targeted reporting. According to policy-makers a forward-looking approach is an important criterion for health reports *(136)*, yet they often lack this kind of information because producing solid and meaningful prognoses is very resource-intensive and requires specialist expertise. Considerable scope therefore exists for combining forces and exchanging experiences in the Region in relation to forecasting, such as the innovative work on qualitative scenario exercises in the Netherlands (see Box 4.2).

Working towards a single health information system for Europe

The WHO Regional Office for Europe, European Commission and OECD have separate health information mandates and activities, but these activities partly overlap, and the three organizations cooperate closely to improve harmonization. A joint data collection project on non-monetary health care statistics is a good example of their close collaboration. In 2010 the intention to strengthen international cooperation in the field of health information was formally endorsed in the Joint Declaration, in which the Regional Office and European Commission agreed to work towards a single integrated health information system for Europe *(126)*. This initiative was joined by OECD in 2012.

Since the Joint Declaration, steps towards creating this system have been taken and the agencies have created a joint roadmap, including the mapping of different and overlapping health

Box 4.1.
Improving quality of care through public subnational reporting in Sweden

Background

The National Board of Health and Welfare is responsible for the transparent publishing of indicator-based evaluations of compliance with national guidelines and subnational comparisons of quality and efficiency of health care in Sweden. For nearly 10 years Sweden has produced reports on health care, public health and social care, and made them available in the public domain in order to improve performance. Subnational comparisons are made in cooperation with the Swedish Association of Local Authorities and Regions; they are updated and published annually. In Sweden, counties and municipalities are responsible for financing and managing health care and social services. Conditions that have been crucial for the development of public reporting include use of a personal identification number for each patient in every registry and access to data: both to mandatory health data and social data registries and to non-mandatory, professionally developed registries on quality of care. These quality of care registries have received substantial funding from the government over the last few years, increasing their utilization.

Key success factors

Thus far the public reporting efforts have been successful. Quality and improvement are on the health agenda, and the results measured by the indicators have improved over time. Several key success factors have been identified, including:

- trust between the actors;
- acceptance of the reported outcomes by professionals;
- awareness that establishing such a reporting cycle is a complex and time-consuming task;
- focusing on quality, guidelines, evidence-based medicine, equity and improvement of work rather than financial incentives;
- involvement and acceptance by counties and municipalities;
- local organizations' use of data to start improvement work.

Public reporting demands extensive communication and networking to create trust and acceptance. A focus on quality issues, improvement efforts and access to data is important, while use of indicators for financial incentives is not recommended. The counties, municipalities and local caregivers need to be involved and have knowledge about improvement techniques and data utilization to implement improvement initiatives. Public reporting is one of many useful tools to improve health information; it should be combined with other tools such as qualitative methods.

information activities. The next phase should encompass the concrete harmonization of these activities. International cooperation is greatly welcomed by countries, which have long been calling for a reduced reporting burden, more efficient use of health information resources and fewer discrepancies between statistics held in the different international databases.

While the intention is to move towards a more integrated system for Europe, this does not mean that all health information activities by the three organizations will be fully integrated; each has its specific mandate and needs to perform activities accordingly. Nevertheless, a fully harmonized set of core indicators, based on a joint data collection and common methods, seems to be a reasonable first step towards this goal. In the short and medium term there is also considerable room for further cooperation and harmonization in knowledge sharing and developmental work in the field of health information, as well as in health reporting activities.

Box 4.2.
A foresight example from the Netherlands: perspectives on future health

In 2014 the National Institute for Public Health and the Environment in the Netherlands (RIVM) published a public health status and foresight report called A healthier Netherlands. To inform this, a trend or business-as-usual scenario was developed, projecting the most important future public health trends, assuming no new or intensified policies. The scenario showed increasing health expenditure, rising numbers of people with long-term illnesses and persistent health inequities. Understanding that prioritizing these issues depends on political and societal values and norms, RIVM initiated an elaborate participation process to draw collective intelligence from stakeholders and experts. This produced four societal challenges for future Dutch public health and health care:

- to keep people healthy as long as possible and to cure illness promptly;
- to support vulnerable people and enable social participation;
- to promote individual autonomy and freedom of choice;
- to keep health care affordable.

These formed the basis of four perspectives on health that provide short narratives of these normative views on future health, each centring on one of the four challenges, entitled "in the best of health", "everyone participates", "taking personal control" and "healthy prosperity". The four perspectives make explicit the diversity in visions that exist, showing that notions such as "health", "prevention" and "health care" have different meanings in each. In the first perspective, for example, health is understood mainly as the absence of disease, whereas in the second, clinical diagnosis is of less importance since social participation is the vital concern.

To identify potential interrelationships between the four perspectives RIVM organized four expert meetings to explore how engagement based on each would affect the other three societal challenges. This approach was designed to clarify areas in which positive spin-offs could occur and productive links be created between perspectives. It would also identify areas in which negative side-effects could arise and where political and other choices or more intensive efforts would be necessary. Taking these anticipated synergies and controversies into consideration, strategic opportunities and options for Dutch public health and health care policies were identified *(137)*.

New approaches to health information and evidence

To optimize monitoring for Health 2020 and beyond, problems related to both existing data collections and new information and evidence requirements must clearly be addressed. Populations are changing, public health concepts are evolving and policies are moving: health information systems need to accommodate these societal shifts. To meet the health information and evidence demands of the 21st century, solid, balanced and integrated systems that produce timely and regular basic health statistics efficiently are required.

At the same time, these systems should be flexible enough to adapt to new policy needs and incorporate non-traditional approaches towards health information and evidence. These seem crucial to meeting the new requirements addressed in this chapter: measuring health and well-being uses subjective measures and qualitative data rather than the traditional quantitative, register-based data used for basic health statistics. This may mean that new data collections need to be developed to meet these new information requirements; perhaps more importantly it also underlines the need to explore non-traditional data sources and new approaches to assessing and interpreting existing data. As illustrated in Chapter 3, the potential of these innovative approaches for unlocking information about the well-being of a population is very promising. Moreover, they may deepen the understanding of morbidity patterns and health behaviours, for example, by adding new angles and additional insights to basic health statistics (see Box 4.3).

The advent of new methods of gathering and analysing health information and evidence is closely linked to the development of information and communication technologies that underpin improvements in clinical care, enable increased access by patients to their own clinical data and extend the reach of health care services to a broader population base. Such technologies are often broadly referred to as e-health. In particular, a growing number of mobile and remotely delivered health (m-health and telehealth) initiatives in Europe are defining new channels for the delivery of health care services and driving new levels of accessibility

to the health care system. To facilitate development of national m-health implementation, WHO and the International Telecommunication Union formed the m-health for NCDs initiative "Be He@lthy, Be Mobile" *(139)*, a landmark joint partnership to scale up successful and cost-effective mobile technologies for NCDs and make them available in different national settings. The initiative focuses on the use of mobile and wireless technology as a platform for delivery of one or more NCD initiatives selected as priority by the country (focusing on, for example, tobacco cessation, diabetes, wellness and diet), and is having a positive and measurable impact on reaching different population groups.

Evidence shows that e-health services are rapidly becoming part of the mainstream across European countries, with several examples of the deployment of technologies for remote treatment and monitoring of patients in their homes, for targeted health promotion activities and as a communication platform for citizen engagement with the health care sector. With the adoption of these new models of health care service delivery come new opportunities

Box 4.3.
The potential of big data for NCD monitoring

Background

Big data is one of several recent technology-based innovations in health that has demonstrated a potential to derive knowledge through a process of discovery based on inputs from traditional and non-traditional information sources. The term "big data" usually refers to data defined by the "four Vs": data of exceedingly high volume that stream in at high velocity in a variety of structured and unstructured formats and are characterized by variable veracity. A technical meeting on the use of big data and social media for NCD surveillance was co-hosted by the WHO Regional Office for Europe and United Nations Global Pulse in September 2013. The goal was to explore the potential application of new data sources – in particular social media, digital trails of daily activities and mass anonymized electronic health record data – to supplement the traditional means of data collection for NCD surveillance.

Outcomes

Social-media data offer the potential of assessing health-related attitudes and behaviours pertaining to NCDs and their risk factors, which can be helpful in measuring trends and shedding light on the public's views on important topics to inform policies and public health campaigns. Data from digital trails (such as mobile phone data, supermarket data and records of credit-card transactions) can offer new insight into aspects of existing health data (including food or other goods purchasing patterns and their changes) and provide access to information on population segments that may otherwise be difficult to survey using traditional health-surveillance methods. Electronic health record systems provide passive, time-continuous data, allowing the observation of short-term medical outcomes and long-term disease trends for near real-time monitoring. Common caveats and restrictions related to the use of big data are privacy and data ownership issues, population biases, a lack of standardization and restrictions regarding the extent to which causal relationships can be established in the data.

Conclusions

Big data from social media, digital trails and other emerging sources have shown their potential as a supplementary source of NCD data, including the capacities for efficient collection and for reaching different population groups. Nevertheless, they should be considered not a replacement for traditional health-surveillance sources but complementary sources of information *(138)*.

for deriving and analysing health information, as well as new demands for greater availability, security and privacy and integration of the information needed in support of clinical care.

The need for international cooperation

Clearly, broad international cooperation is required to efficiently and sustainably address the health information challenges described in this report. Harmonization, cooperation and the sharing of knowledge, experiences and good practices are essential. These will strengthen national health information systems, which in turn will lead to improved data collections at the international level.

The WHO Regional Office for Europe, the European Commission and OECD, by working to develop the single integrated health information system for Europe, acknowledge this need for international cooperation. Nevertheless, countries must steer the development of this endeavour, which will inform policy at the national as much as the international level. In addition to governmental authorities, expert input from public health institutes, statistical offices and academia is essential.

European Health Information Initiative (EHII)

EHII is a WHO network committed to improving the health of people in the European Region by improving the information that underpins policy. With the Ministry of Health, Welfare and Sport in the Netherlands, the WHO Regional Office for Europe launched EHII in 2012 to develop the broad stakeholder base throughout the Region. EHII members include Member States, WHO collaborating centres, health information networks and other stakeholders. In addition, the European Commission and OECD support EHII and attended the first meeting of its steering group in March 2015.

EHII works in six key areas, described further in the following subsections:

- development of information for health and well-being, with a focus on indicators;

- enhanced access to and dissemination of health information;
- capacity building;
- strengthening of health information networks;
- support for health information strategy development;
- communication and advocacy.

1. Development of information for health and well-being, with a focus on indicators

Chapter 3 of this report is devoted to outlining priorities for the first of these important key areas. In addition, quantifiable measures for Health 2020 concepts that have not previously been measured routinely need to be addressed, such as resilient communities, empowerment and supportive environments. Alongside this innovative work, EHII also supports work on existing data collections and has planned an evaluation of the European Health for All database.

2. Enhanced access to and dissemination of health information

A major tool for this area is the WHO health information and evidence portal on the WHO Regional Office for Europe website (see Fig. 4.1). It is a one-stop-shop for easy access to European health information and policy-relevant evidence. While the basic technical infrastructure of the portal is in place, links need to be established with expert networks and research groups to create co-ownership for specific content parts of the portal. Keeping the content up to date – always the main challenge for such an initiative – cannot be achieved without the involvement of the Region's leading groups of public health experts.

Facilitating the exchange of national experiences should also be prioritized when developing this second key area. One way this will be achieved is through the Regional Office's new public health and policy journal, *Public Health Panorama*. This focuses on sharing countries' experiences of health policy development and implementation, facilitating an exchange of ideas between the western and eastern parts of the Region. Contributions are accepted in both Russian and English and all papers are published in both languages.

HEN is another key platform for enhancing access and disseminating health information. HEN provides evidence in multiple formats, such as synthesis reports and policy briefs, to aid decision-making *(28)*.

3. Capacity building

The annual WHO Autumn School on Health Information and Evidence for Policy-making (see Fig. 4.1) is an important first step in this key area towards improving health information knowledge and skills in countries in the Region. A considerable need for more training and support exists, however – for example, in relation to coding and quality assessment of cause-of-death data and in monitoring health inequities. To meet such needs WHO will continue to develop multicountry workshops in close consultation with Member States. These should target specific learning needs and continue to support individual countries through the bilateral country agreements.

Another essential activity to stimulate capacity building is the development of high-quality training materials and teaching modules that can be shared via the WHO health information and evidence portal to expand expertise. Health information staff can work with the materials directly, and WHO workshop attendees can use them to organize subsequent workshops in their countries. The materials will be produced in English and Russian, as a minimum, to enhance their usability throughout the Region.

4. Strengthening of health information networks

EHII is committed to supporting the establishment of more multicountry networks; these facilitate sharing experiences and joining forces while tackling common health information problems. As such, they contribute to the improvement and sustainability of both national and international health information systems. One example is the Central Asian Republics Health Information Network (CARINFONET), which was re-established in June 2014 and is supported by the WHO Regional Office for Europe. CARINFONET will improve the collection, use and distribution of accurate and timely information. It will assist health policy-makers within and across central Asian countries in monitoring trends in health, disease and well-being. The activities

of such networks should be aligned with other EHII key areas to achieve maximum efficiency and harmonization of health information activities across the Region.

The Evidence-informed Policy Network (EVIPNet) is another key network underpinning the EHII, promoting the systematic use of health-research evidence in policy-making. Launched in the European Region in October 2012, it encourages the development of country-level teams comprising policy-makers, researchers and representatives of civil society. These teams facilitate policy development and implementation through the use of the best available global and local evidence. EVIPNet builds capacity in countries to establish mechanisms to translate evidence into policy, such as through the development and use of evidence briefs for policy and policy dialogues. At the time of writing the EVIPNet Europe network consisted of 13 European Region countries in eastern Europe and central Asia, four of them piloting its methodology. Since evidence-informed policy-making is needed across the Region, an important goal of EVIPNet Europe and EHII will be to expand the network, especially to western EU countries, thus creating an opportunity for them to learn from the experiences of the pilot countries.

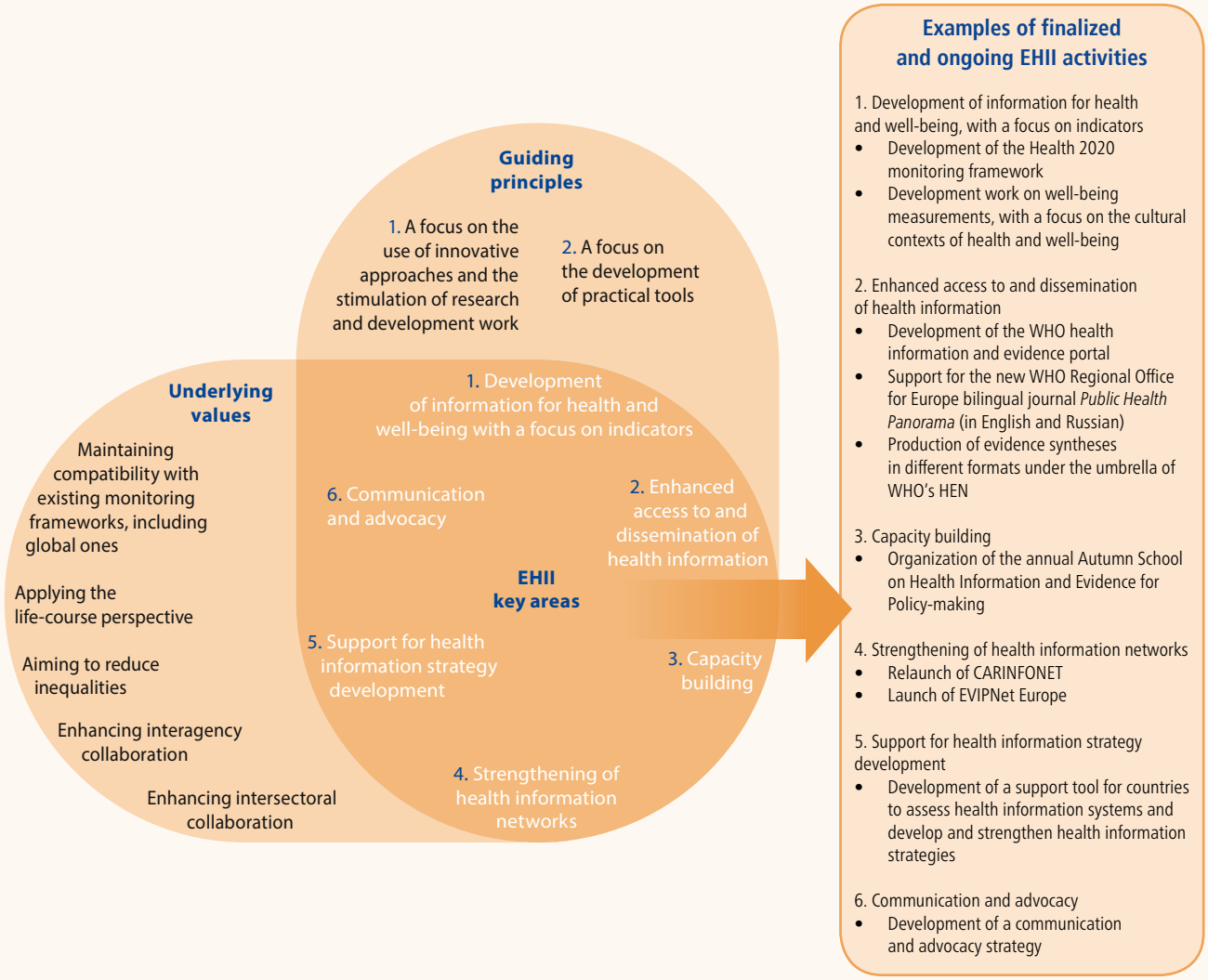
5. Support for health information strategy development

The fifth EHII key area is support for system assessments and strategy development. National health information systems are not commonly underpinned by a dedicated, broadly supported strategy; instead, they tend to reflect a conglomerate of different activities and stakeholders without a common vision and development agenda. This can mean that decisions regarding the downsizing or development of health information activities are taken on an ad hoc basis, rather than guided by a comprehensive strategy that outlines the priorities for current and future activities. Moreover, many health information needs may place significant demands on systems, making it hard to get an overview of the whole picture and prioritize.

To improve this situation the WHO Regional Office for Europe and a dedicated group of experts developed a support tool for countries (see Fig. 4.1) *(140)*. Based on work by the WHO Health Metrics Network, the tool aids countries in assessing

health information systems and developing and strengthening strategies. As they gain experience in using the tool, countries will play a key role in shaping and updating it, as well as populating it with examples of good practice. The WHO health information and evidence portal would be an excellent way of disseminating these supplementary tools.

Fig. 4.1.
The EHII key areas and examples of finalized and ongoing activities within each



6. Communication and advocacy

The last key area includes communication about both EHII outputs to optimize their use and EHII itself to inform health information stakeholders and enhance the network. A communication and advocacy strategy covering both these elements is being developed. It will include activities such as setting up an EHII website, developing a plan for the structural use of the WHO health information and evidence portal as a central means of disseminating EHII products, and presenting EHII at various events.

The health information research and development agenda: next steps

Ensuring that health information systems are fit for the 21st century requires renewed effort. Existing data collections need to be strengthened and improved, and innovative measures and approaches developed. Action is needed across the six EHII key areas and at different levels – for example, bilaterally between WHO and Member States, in multicountry networks and in collaborative efforts between international stakeholders. Existing work in this area will be built on.

Member States, with the WHO Regional Office for Europe and other stakeholders, need to determine the priorities of the health information research and development agenda for the European Region over the next few years. EHII should be the key driver in this, ensuring coherence and coordination between different health information activities in the Region and linking them to the development of the single European health information system.

Momentum for EHII is growing, but more members are needed to strengthen the network and increase its capacity to ensure that health information activities in the Region are improved across all its six key areas. Only by joining forces and sharing knowledge and experiences can health information be improved in an efficient, sustainable and coherent way.