

05

**THE UNFINISHED AGENDA
BEYOND 2020 –
WHAT DO WE NEED
TO DO NEXT?**



Health 2020, the European policy framework for health and well-being, has been a catalyst for strengthened public health action in the European Region. It has also brought the use of information and evidence to the forefront of European public health thinking and policy-making through its accountability mechanism, the Health 2020 targets and indicators. These were adopted by the 53 Member States of the European Region in 2013 (174) and have been monitored on a regular basis ever since. Health 2020 also placed new emphasis on measuring health and well-being instead of merely focusing on the measurement of death, disease and disability. This accords with the WHO definition of health as not merely the absence of disease and infirmity but physical, social and mental well-being. This reflected a paradigm shift in the approach to public health and was facilitated by the introduction of the cultural context of health in the Regional Office's work, the increased use of qualitative information and reporting using new kinds of evidence from the medical humanities, including narratives, and the establishment of the unique multipartner WHO European Health Information Initiative (EHII) to coordinate and harmonize health information in the Region.

These developments are absolutely critical if the European Region is serious about reducing health inequalities and reporting on them. As Sir Michael Marmot said, "in order to reduce inequalities in health, we must first address the inequalities in health information. Where health information is poorest, health is also poorest" (184). The Sustainable Development Agenda 2030 has lent further support to this approach through its detailed monitoring requirement on goals and targets, using more than 300 indicators. Such reporting requirements necessitate not only strong infor-

mation systems for health at the country level but an increased use of information and evidence for policy-making. For this reason, the European Member States adopted the European Action plan to strengthen the use of information, evidence and research for policy-making in 2016 (39). This action plan is unique and Europe is the only WHO Region to have ever put such a plan forward. It is, however, crucial in order to ensure not only the generation of high quality information at the country level through routine reporting, digital health¹⁰, and research, but also the translation of evidence into policy. Given these innovative and trailblazing initiatives in health information and evidence, is the European Region on course to achieve its goals and will it be able to effectively report on them under Health 2020 and Agenda 2030?

Reporting requirements are increasing for Member States with more and more monitoring frameworks coming into focus. Many of these overlap and duplicate or even triplicate the same indicators. Understandably, the Member States of the European Region therefore requested that the Regional Office propose a reductionist approach to reduce the reporting burden. This resulted in the establishment of a joint monitoring framework for Health 2020, the SDGs and the Global framework to reduce noncommunicable diseases. The Regional Office has also established a gatekeeper function to ensure that data requests are only made to Member States when required by governing bodies' decisions and resolutions. This comes at a time when demands for action in public health become more and more intersectoral, thus also necessitating intersectoral measurement and reporting. Moreover, the landscape of "data analysts" is also expanding with institutions such as the Institute for Health Metrics and Evaluation

10 The terms eHealth and digital health are used interchangeably in this report, reflecting their evolution and the discussion among Member States at the 71st World Health Assembly.

(IHME), which provides valuable global, regional and national assessments on burden of disease. The WHO Regional Office for Europe collaborates closely with IHME and has established a European Burden of Disease Network co-hosted with the institute to enhance collaboration and strengthen the generation and use of burden of disease data at the country level.

In addition, new kinds of data are flooding the health information market through big data which draws on a myriad of sources and data types, raising new possibilities and threats which have not yet been clearly defined for public health. Big data and the associated emerging field of data science have been receiving a lot of attention as potential new sources of information for sustainable development efforts – outside routine information systems (175, 176), in official statistics (177, 178), and to inform policy-making (179). Consequently, there have been some reviews to take stock of the current barriers to, and opportunities for, the use of big data in government, including case studies on using big data sets for public health and the provision of health care (180–182).

However, despite many promises of the potential gains that big data can offer in relation to Health 2020 policy objectives or achieving Agenda 2030, these are yet to be fully explored. For example, there is still no clear and unanimously agreed definition for the use of big data for health, nor is there a vision of how health information systems can use the innovation and advances coming from big data and associated developments, such as for data governance, ethics, technology, interoperability and analytics.

The current discussions around data innovation reflect the diversity of opportunities in using big data as a source of information, and the challenges this poses to the systematic use of information for policy-making. Statistical offices

are exploring the possible use of new data sources for official statistics. Monitoring progress towards meeting the SDGs will require the collection of data for a large number of indicators that, in many countries, are currently not routinely available or not available at the expected level of disaggregation. The Global action plan for SDG data (178) includes a commitment to develop principles for incorporating new and innovative data into official statistics.

While societies demand higher levels of transparency of health information and the way it is used for policy-making, national authorities face increasingly stringent data privacy and protection laws. Countries vary enormously in the way data for health are collected, integrated and reported. Scandinavian countries use personal identifiers which enable all the data collected on each citizen to be linked for administrative use and also for the assessment of health and care needs in the population. Other countries neither link nor collect information for health through single and integrated systems, permitting only aggregated analyses of data at the population level. Countries and international organizations struggle to balance meaningful reporting with data privacy requirements while at the same time trying to respond to increasing requests for transparency. This is particularly pertinent when countries use and present subnational or local data where it could be possible to identify population groups or even individuals. The use of local data for local decision-making, however, is highly desirable and a key element of the implementation of the Action plan to strengthen the use of evidence for policy-making in European countries.

The goal to harmonize health information from all Member States, to make it comparable and easily accessible, has not been abandoned but has proved a much greater challenge than anticipated, even with the advantage of new technologies for

interoperability of systems, greater opportunities for data sourcing, novel analytical techniques and harmonization of information. Member States have clearly expressed their wish to see the establishment of such a system through the resolution that accompanies the European action plan and that future health information developments in the European Region should be conducted under the umbrella of the EHII in order to avoid duplication and an increased reporting burden on Member States. This also requires stronger national health research systems and dedicated health research strategies (see Chapter 4). The latter are only available in a very few European countries but are a necessity if countries wish to adopt a systematic approach to the generation and use of research for health policy-making. The European Health Research Network was launched to achieve precisely that (183).

Quantitative data, including on mortality, morbidity and disability, remain at the core of health reporting and are absolutely essential when assessing the health of a population. As discussed in Chapter 4, they do not, however, explain the full picture and describe the “what” and “how much” rather than explain “why” certain trends are observed. In order to interpret the quantitative information adequately and understand why trends occur, qualitative information is also required. This, however, rarely comes from the health sector and requires information and evidence from the medical humanities and social sciences. It also requires different kinds of information such as narratives, particularly in the interpretation of well-being and the new concepts enshrined in Health 2020, such as community resilience, empowerment, the life-course approach and the whole-of-society approach, as described in Chapter 3. Through a series of expert group meetings, the Regional Office has defined these concepts and is now using them in the monitoring of progress of Health 2020. Both kinds of

evidence – numbers and narratives – have to become mainstream information and evidence to strengthen policy-making for public health in the 21st century. Further, both have to be brought to the attention of all stakeholders, including the general public, to engage in a meaningful debate about what this information means for communities, families and individuals. Iceland (Box 5.1) could serve as a good case study in this regard, as all information for health generated by the authorities is discussed with local communities in town hall meetings. The implications of the results are discussed and decision-making is informed by these interactions, thus implementing the whole-of-society approach advocated by Health 2020.

More serious thought needs to be given to the communication of health information, far beyond the use of images or infographics. This may involve story-telling techniques and face-to-face meetings with local communities about their health experience, as is done in Iceland. Such efforts would lead to a demystification of statistics into actual knowledge used by all, thus creating a new paradigm of “evidence for all”. It would also ensure that systems are not merely created for themselves or for the use of international and national authorities but for the express purpose of bringing data to the individual. Various efforts have been made to bring evidence to the people, some of them through social media and mobile applications. However, they tend to be largely based on statistics or images and only a few use unconventional techniques, such as narratives. It is a challenge for any national or international authority to attempt this and it requires some really innovative thinking. Under the EHII, WHO has recently established a think tank to explore these possibilities for internationally and nationally reported information. This group is exploring new ways of communicating information for health and well-being and innovative channels to bring information to the people and thus achieve the goal of evidence for all.

Box 5.1. Linking data to action in Health-promoting communities in Iceland

In 2016 the Directorate of Health (DOH) in Iceland started publishing annual subnational public health indicators for the country's seven health districts. Their format is based on examples from other countries, e.g. Norway and the UK. Monitoring relevant public health indicators at the subnational level, as well as the dissemination of data to stakeholders, is an effort towards minimizing regional health inequalities. In recent years the DOH has put emphasis on developing the programme "Health-promoting community" (HPC), through which data, research and policy are linked to action. The main aim of the programme is to support committed communities to create supportive environments that promote healthy behaviour and lifestyles, health and well-being for all its inhabitants. As of April 2018, approximately 80% of the Icelandic population were living in communities designated as an HPC.

Subnational public health indicators assist local authorities to assess the health situation in their communities, identifying their strengths and weaknesses and gaining better insight into the needs of their inhabitants. The DOH has organized local workshops in which the interpretation of individual indicators has been discussed along with the rationale for their inclusion.

The process of developing the indicators has revealed several important points. These include the realization that it is crucial that the health districts and municipalities themselves use indicators provided by the DOH to carry out their local analysis in comparison to the country as a whole. They then have to interpret the results based on their knowledge of the local community. Is the situation acceptable, and if not how can it be improved? In order to facilitate this work, checklists, an online shared working area and other support tools are being developed. These are intended to assist local authorities with further situation analyses, to plan and act based on the best available knowledge and evaluate the work being done to improve the health and well-being of the inhabitants.

Subnational health indicators bring to light weaknesses and identify challenges. Their publication has drawn media attention. There have already been several cases where communities have taken on these challenges, with support from the HPC programme, to systematically work towards improved health and well-being for their inhabitants.

As work on the development of subnational public health indicators and effective knowledge translation continues to expand there has been an increased demand for data by smaller communities. An effort is made to meet these demands, the rationale being that more locally relevant data may increase the inhabitants' involvement in the effort.

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