Blueprint for actions to enhance the organization of national HESs in the EU Member States

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Disclaimer

The views expressed here are those of the authors and they do not represent the Commission’s official position.

Acknowledgement

The work on this report has been supported by the funding from the EC/DG SANTÉ through BRIDGE Health project (no. 664691).

Cover illustration edited by Hanna Tolonen from vector graphics by Freepik.

April 2017 – Helsinki, Finland
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Introduction
An increasing number of EU Member States have conducted or are planning to conduct national health examination surveys (HESs). The Feasibility of a European Health Examination Survey (FEHES) project was conducted in 2006-2008 to assess the importance of national HESs and the importance and feasibility of their joint standardization. (Tolonen et al. 2008a, Tolonen et al. 2008b) It was followed by the European Health Examination Survey (EHES) Pilot Project in 1999-2002 in which survey guidelines were prepared and a pilot survey was conducted in 13 countries. (Kuulasmaa et al. 2012)

During the EHES Pilot Project, also the EHES Coordinating Centre (first called the EHES Reference Centre) was established at the National Institute for Health and Welfare in Helsinki, Finland. It was meant to coordinate the EHES network, maintain and update the EHES Manual, maintain and update the training programme, provide professional support to the countries planning national HESs, coordinate external quality control and prepare guidelines for and monitor of internal quality control, evaluate and document the success of the standardization, and to report basic survey results at the European level.

After the EHES Pilot Project, the joint standardization of national HESs, and some of the activities of the EHES Coordinating Centre were continued as a part of EU’s BRidging Information and Data Generation for Evidence-based Health policy and research (BRIDGE Health) project in 2015-2017. Under the framework of the BRIDGE Health project, the EHES network has been updated, the EHES website has been updated and maintained, the EHES Manuals have been updated and related training material is being updated, e-mail consultations for countries planning and organizing their national HES have been provided and some external quality control measures such as site visits and laboratory quality assessment have been conducted.

This document, prepared within the BRIDGE Health project, summarizes key European level actions needed to enhance standardization of national HESs in all EU Member States. The current status of these actions is categorized into;

- **Operational**
- **Partially operational: but requiring further development**
- **Planned actions**

Recommendations are given on how these actions should be organized in the future.
Actions

Availability of guidelines and standardized protocols
Guidelines for planning and organizing a national HES and standardized protocols for the measurements and collection of biological samples help countries to implement such a survey. Their aim is to enhance comparability of survey results and benchmarking between countries.

Description of the action
Guidelines for organizing a national HES have been developed and are available in the EHES Manual, Part A. Planning and preparation of the survey (Tolonen, 2016a). It covers:

- selection of target population and sample size;
- sampling procedures;
- legal and ethical aspects;
- selection of questionnaire modules, clinical measurements and biological samples,
- timing of the fieldwork;
- selection of the examination site and the fieldwork staff;
- questionnaire design and administration;
- quality assurance;
- data management;
- recruitment of participants;
- dissemination and publicity;
- training of the survey organizers and fieldwork staff; and
- budget.

Standardized protocols for EHES core measurements and collection of biological samples are available in the EHES Manual, Part B. Fieldwork procedures (Tolonen, 2016b). This includes protocols for:

- anthropometric measurements (waist and hip circumferences, height and weight),
- blood pressure
- tests of functional capacity (hand grip test and chair stand test),
- collection of blood (total and HDL cholesterol, fasting glucose and HbA\textsubscript{1c} and urine (first morning, spot and 24 h) samples (sodium), and
- a standardized core questionnaire (mainly based on the European Health Interview Survey (EHIS) questionnaire).

These were developed and tested in the EHES Pilot Project and updated in 2016.
A library of **existing international standard protocols/standard questionnaire modules for additional measurements** would be needed to cover other key public health issues such as physical exercise, alcohol use, mental health and other aspects of functional capacity (e.g. cognitive capacity). These are often included in national surveys, but for many of these, there are currently no European/international standards.

A library of **health measurements included in previous national HESs** would be helpful to enhance standardization and share experiences between countries. The library should include a possibility to search for specific measurements of interest. Based on information collected to this library a review of health measurements included in previous national HESs could be conducted and published. Such information was previously collected and regularly updated in the EUHSID project (the HIS/HES) database (https://hishes.wiv-isp.be), but these have not been updated since 2010.

Many of the national HESs have prepared extensive **methodology reports** or standard operating procedures (SOPs) for their surveys including information about sampling, recruitment and measurement procedures. Some of these are publicly available, whereas some are available only for the local survey team. Some have been prepared in or translated to English. A library of such reports would help others to get started with the planning of their HESs and allow opportunities for benchmarking. It would also encourage others to prepare their methodology reports in English and make them publicly available.

### Current status and future needs

<table>
<thead>
<tr>
<th>Action</th>
<th>Current status</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guidelines for organizing a national HES (EHES Manual, Part A).</td>
<td><strong>Operational</strong></td>
<td>Periodic updating is needed.</td>
</tr>
<tr>
<td>Standardized protocols for EHES core health measurements and collection of biological samples (EHES Manual, Part B).</td>
<td><strong>Operational</strong></td>
<td>Periodic updating and adding new measurement protocols based on national needs is required.</td>
</tr>
<tr>
<td>Library of existing international standard protocols/standard questionnaire for additional survey modules to the EHES web site.</td>
<td><strong>Planned</strong></td>
<td>A library of protocols/questionnaire modules should be established to the EHES web site.</td>
</tr>
<tr>
<td>Library of health measurements included to previous national HESs</td>
<td><strong>Partially operational</strong></td>
<td>A summary list of the most frequently included measurements already exists in the EHES web site but this should be further developed to include survey specific information.</td>
</tr>
<tr>
<td>Library of methodological reports of previous national HESs</td>
<td><strong>Planned</strong></td>
<td>Collection of or links to methodological reports should be established in the EHES web site and countries should be encouraged to prepare and publish their methodological reports.</td>
</tr>
</tbody>
</table>
Network of national HES organizers
Networking is an effective way to exchange information. A network of people organizing and working with HES data can enhance exchange of information and create new collaboration to solve existing challenges and problems.

Description of the action
EHES Network is intended to include survey organizers of the countries which have conducted national HESs and representatives from other EU Member States. It can share experiences to enhance application of best practices and standardization. Sharing experience is important especially for the countries which are planning their first national HES. The network can also help more experienced countries to solve common challenges such as decreasing response rates.

A face-to-face network meeting once a year could help experts from different countries to get to know each other, which lowers the threshold for personal communications. Each meeting would address a few key topics on which the countries could share their experiences. Examples of such topics are recruitment methods, equipment validation for blood pressure measurement, and storage and transfer of biological samples from fieldwork sites to central laboratory.

Between these meetings, an internet based discussion forum or some other user friendly platform could promote discussions. The internet site could also have a FAQ section.

Current status and future needs

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<tr>
<th>Action</th>
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<th>Recommendations</th>
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<tbody>
<tr>
<td>EHES Network</td>
<td>Operational</td>
<td>Regular updating of the network is needed.</td>
</tr>
<tr>
<td>Network meetings</td>
<td>Planned</td>
<td>Annual network meetings should be organized.</td>
</tr>
<tr>
<td>Internet based tools and platforms to share experiences between network members</td>
<td>Planned</td>
<td>Internet based platform or forum for discussions and FAQs should be established.</td>
</tr>
</tbody>
</table>
Professional support by EHES Coordinating Centre

Description of the action
After the EHES Pilot Project, the EHES Coordinating Centre has provided e-mail consultation for countries planning and organizing their national HESs. The service has not been widely promoted due to limited resources. The survey organizers have sought consultation on questions related to sampling, handling of biological samples, measurement protocols, questionnaires etc. There seems to be clear demand for this type of service.

Personal consultation visits to the countries planning their national HESs would be beneficial since this would allow deeper discussions on any relevant topics on one occasion. A few such consultation visits have been done with financial support (travel expenses) by the countries requesting help.

In the future, it would be a natural task of the EHES Coordinating Centre to coordinate such visits. They could be carried out by experts from the EHES Coordinating Centre or by experienced national survey organizers from other countries.

Current status and future needs

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<th>Recommendations</th>
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<tbody>
<tr>
<td>E-mail consultations</td>
<td><strong>Operational</strong></td>
<td>To ensure sustainability of the action, the personnel resources should be funded.</td>
</tr>
<tr>
<td>Personal consultation visits</td>
<td><strong>Planned</strong></td>
<td>Required personnel resources should be secured for coordinating and conducting the visits.</td>
</tr>
</tbody>
</table>
Quality assurance

Quality assurance covers the measures that help to ensure a high quality of the collected data and to demonstrate the achieved quality. Its main components are the availability of guidelines and standardized procedures (described above), training, quality control and assessment of the achieved quality. We will consider here quality assurance measures that are relevant at the European level.

Description of the action

**European level training seminars** were organized during the EHES Pilot Project. These were targeted to national trainers, who trained the national survey teams: there was one on survey organization and another on fieldwork protocols. The EHES Manual outlines three training seminars which would be needed at the EU level but due to lack of funding have not been organized after the EHES Pilot Project. These seminars would cover the following topics: 1) planning and preparing for the European Health Examination Survey (EHES) at the national level, 2) field work of the national health examination surveys, and 3) data management, validation and analysis, and reporting and dissemination of results.

**EHES Training materials** (PowerPoints, videos and knowledge tests) are available on the EHES web site for key topics related to the organization of national HESs and for all core measurements. They aim to promote correct application of the standardized protocols given in the EHES Manual. These materials are in English but countries are encouraged to translate them into their own language and adapt them (e.g. specifying the devices) whenever needed. These were developed during the EHES Pilot Project and updated in 2017.

**Site visits** during the fieldwork periods of national HESs have been organized since the EHES Pilot Project. One or two persons from the EHES Coordinating Centre have observed the fieldwork with the consent from the fieldwork staff and survey participants. One day is usually spent on observing and documenting the fieldwork to evaluate adherence to the standardized protocols, interaction between fieldwork staff and participants, organization of the fieldwork site and the general atmosphere on the fieldwork site. The second day is spent with the personnel of the national coordinating office discussing issues such as planning of the survey, ethical issues, sampling, recruitment of invitees, training of the fieldwork staff, data management etc. Also feedback from the observation of the fieldwork is provided. After the visits, the observations, discussions and recommendations for improvement are documented on a site visit report. Currently, the site visit reports are confidential and shared only between the EHES Coordinating Centre and the specific national survey organizers. The site visit observations during the EHES Pilot Project have been summarized in the article published in the European Journal of Public Health. (Tolonen et al., 2017)

The site visit reports help to demonstrate how well the surveys are conducted and how comparable they are with other national HESs in EU. They have also been useful to evaluate the feasibility of the standards and recommendations, and help to identify needs for updates of the EHES manuals, training materials and development of European level coordination actions.

**Quality assessment reports** document and assess the obtained quality and country-specific characteristics of the collected HES data. For the evaluation of the quality, information about used data collection procedures are combined with quality indicators derived from the individual level data, to derive summary quality indicators for each data item.

The outline for these quality assessment reports was prepared during the EHES Pilot Project and it is documented in the EHES Manual but actual reports have not been prepared and published.
The laboratory quality assessment scheme was developed and tested during the EHES Pilot Project to provide valuable information about comparability of cholesterol and glucose measurements between different laboratories. The EHES Reference Laboratory in the EHES Coordinating Centre prepared a set of test samples which were sent, with blinded reference values, to the national HES laboratories for their analysis. National HES laboratories analysed the test samples together with their survey samples and sent the measurement values back to the EHES Reference Laboratory which evaluated the results against the reference values and provide feed-back to the national laboratories.

Some countries which have conducted national HESs after the Pilot project have also requested a laboratory quality assessment from the EHES Reference Laboratory. This indicates a continued need for such a service.

Current status and future needs

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<tr>
<th>Action</th>
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<th>Recommendations</th>
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<tbody>
<tr>
<td>European level training seminars (to train the national trainers)</td>
<td>Partially operational</td>
<td>A framework for training seminars has been established, and an infrastructure to support regular organization of EU-level training seminars should be established.</td>
</tr>
<tr>
<td>Training materials (PowerPoints, videos and knowledge tests)</td>
<td>Operational</td>
<td>Periodic updating and adding new training materials for new measurements is needed.</td>
</tr>
<tr>
<td>Site visits</td>
<td>Operational</td>
<td>For each national HES, at least one external site visit should be conducted by the EHES Coordinating Centre. Site visits should be further developed to allow the publication of the reports in the web for others to learn.</td>
</tr>
<tr>
<td>Quality assessment reports</td>
<td>Partially operational</td>
<td>An infrastructure for timely preparation and publication of quality assessment reports should be established.</td>
</tr>
<tr>
<td>Laboratory quality assessment</td>
<td>Partially operational</td>
<td>A procedure for quality assessment has been established and tested. The EHES Reference Laboratory for lipid and glucose measurements should be resourced for continuous action to ensure comparability of these measurements between surveys.</td>
</tr>
</tbody>
</table>
Data sharing and joint reporting

Description of the action

**Common definition of indicators** helps to enhance comparability of reported information. For EHES core measurements, standardized definitions for the indicators are given in the EHES Manual, Part C. These are in line with the European Community Health Indicators (ECHI).

During the EHES Pilot Project, **R-programme code** was prepared and published in the EHES Manual, Part C for those core indicators.

**Sharing of individual level data** from the national HESs with the EHES Coordinating Centre is a prerequisite for proper assessment of the quality and comparability of the HES data. It would also facilitate joint EU-level reporting of health indicators derived from HESs. Furthermore, it would simplify technically the sharing of the data with research groups for further analysis.

The EHES Pilot Project drafted principles for data sharing. As a part of this, templates for data transfer agreements for the national survey data were prepared. The participating countries provided the EHES Coordinating Centre with a copy of the pilot survey data set in a standardized format, and these data were used for testing the data assessment procedures and for joint analysis for publications.

The development of a distributed database could be considered as an alternative to the physical transfer of the data files. A distributed database consists of a network of database servers, one in each country. The national data of each country would stay in a standardized format in the national server, but authorized users from other servers could analyse the data from multiple countries as if they were all located in one place.

A **joint reporting system** which would allow timely joint reporting of basic results from the national HESs was planned during the EHES Pilot Project. The system creates a database of the indicators which can then be reported in different formats in different reporting platforms. The primary reporting platform in mind at the time of the Pilot Project was HEIDI ([https://webgate.ec.europa.eu/sanco/heidi/index.php/Main_Page](https://webgate.ec.europa.eu/sanco/heidi/index.php/Main_Page)), which was being planned by the European Commission. HEIDI has later been replaced by the ECHI data tool ([http://ec.europa.eu/health/indicators/indicators_en](http://ec.europa.eu/health/indicators/indicators_en)), but also more flexible reporting tools should be considered.

The countries which have conducted national HESs have prepared **reports about their key results** or published such results in scientific articles. The key results concern population and population sub-group prevalence’s or mean values of the core measurements and possibly also regional and/or socioeconomic differences and changes over time. A library of such national reports could help to develop the national and European level reporting, and facilitate comparisons between countries.

Current status and future needs

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<th>Recommendations</th>
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<tbody>
<tr>
<td>Common definition of indicators for EHES core measurements (EHES Manual, Part C.)</td>
<td>Operational</td>
<td>Requires regular updating and further development.</td>
</tr>
<tr>
<td>Programme codes to calculate</td>
<td>Operational</td>
<td>Requires regular updating and further</td>
</tr>
<tr>
<td>Action</td>
<td>Current status</td>
<td>Recommendations</td>
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<tr>
<td>common indicators</td>
<td></td>
<td>development.</td>
</tr>
<tr>
<td>Centralized database</td>
<td>Partially operational</td>
<td>A framework for centralized database was developed during the EHES Pilot Project. It should be further developed to facilitate quality assessment of the data, joint reporting and data sharing for research purposes. Sustainable infrastructure for data storage and sharing in needed.</td>
</tr>
<tr>
<td>Joint reporting system</td>
<td>Planned</td>
<td>Sustainable infrastructure for the reporting system is needed. Also needed is collaboration with available reporting platforms for the joint reporting (e.g. the ECHI data tool).</td>
</tr>
<tr>
<td>Library of key results from previous national HESs</td>
<td>Planned</td>
<td>A list of publications/reports including key results from previous national HESs should be established to the EHES web site</td>
</tr>
</tbody>
</table>
Experiences on the uses of HES results to support health policies

Examples from other countries about how HES data has been used to support health policy decisions and clinical work can help countries getting political and financial support for their national HES by demonstrating the potential benefits of such a survey.

In addition to the national uses of the data, the European Union has recognized the need for health data and developed the ECHI indicators (http://ec.europa.eu/health/indicators/indicators_en) and the ECHI data tool (http://ec.europa.eu/health/indicators/indicators_en) - for health information which have been deemed important by the Member States. For some of the ECHI indicators, such as on blood pressure, reliable data can be obtained only from HESs. Similarly, WHO and OECD are collecting and dissemination health information from the national data sources. The monitoring of WHO's voluntary targets for the prevention of non-communicable diseases by year 2025 rely heavily on HES data. The National Health and Nutrition Examination Survey of the USA has been conducted since the 1960s and is an integral part of the country’s health monitoring system.

Description of the action

In many countries, National HES data have been used extensively not only for monitoring and epidemiological research but also to identify new, emerging public health problems, project future public health problems, define reference values, prepare risk calculators for clinical use, and to prepare clinical treatment guidelines. Examples of uses of HES data would help all countries to use their HES data more effectively to support public health decision making and for research. Furthermore, HESs have been important for the evaluation of many population based intervention studies focusing on disease prevention (e.g. the North-Karelia Project (Puska et al, 2009), the Finnish Diabetes Prevention Study and the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (https://www.thl.fi/fi/web/thlfi-en/research-and-expertwork/projects-and-programmes/finger-research-project)).

Current status and future needs

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<th>Action</th>
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<tbody>
<tr>
<td>Library of national/international clinical treatment guidelines which have used research evidence from HES data</td>
<td>Planned</td>
<td>A list of guidelines should be established to the EHES web site.</td>
</tr>
<tr>
<td>Library of risk calculators based on national HES data</td>
<td>Planned</td>
<td>A list of risk calculators should be established to the EHES web site.</td>
</tr>
<tr>
<td>Library of examples of key public health problems identified through national HES data</td>
<td>Planned</td>
<td>A list of examples should be established to the EHES web site.</td>
</tr>
<tr>
<td>Library of reference values based on national HES data</td>
<td>Planned</td>
<td>A list of reference values should be established to the EHES web site.</td>
</tr>
<tr>
<td>Library of uses of HES data for intervention studies</td>
<td>Planned</td>
<td>A list of intervention studies, where HES data have been used to evaluate the outcomes should be established to</td>
</tr>
<tr>
<td>Action</td>
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<td>the EHES web site.</td>
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Usefulness of proposed actions

On 5th April 2017, a short questionnaire about usefulness of proposed actions to enhance organization of national HESs was mailed to the EHES network. Network members had until 25 April 2017 to reply the online questionnaire. A total of 16 replies were received; 12 of them were from countries which have conducted a national HES and four from countries which have not conducted a national HES.

Figure 1. provides results for each action listed in the questionnaire. Overall, the proposed actions were in general seen either very useful or somewhat useful when planning and organizing a national HES.

![Classification of usefulness of proposed actions by EHES Coordinating Centre to enhance the planning and organization of national HESs in EU Member States](image)

**Figure 1.** Classification of usefulness of proposed actions by EHES Coordinating Centre to enhance the planning and organization of national HESs in EU Member States

The availability of guidelines for organization of a national HES, standardized protocols for EHES core measurements and common definitions of indicators for EHES core measurements were rated as very useful in at least 80% of the replies. Also e-mail consultations on specific questions were seen useful by almost 80% of the replies.
Conclusions and discussion

National HESs have been conducted in 15 EU Member States since year 2000 (Figure 2). This indicates a strong need for such surveys as a part of the national health monitoring system in these countries. The countries and the European Commission (EC) have also indicated the importance of comparability of the data collected by surveys between countries and over time. This initiated the EHES process of joint standardization of the national HESs. The required infrastructure was mostly set up during the EHES Pilot Project. The challenge now, when the system has been set up and countries are strongly relying on it, is to develop EHES into a sustainable system in order to support the countries in conducting periodic HESs and to help to set up national HESs in countries without past experience on them.

In the current report, we summarized the status of the EHES process and specified a set of concrete actions that are needed to ensure equal opportunity for all EU MSs to organize a national HES, i.e. complete the process of EHES standardization and coordination and make it sustainable. The key issue now is to get these actions funded, not only through temporary project funding but as part of a sustainable EHES system. The most feasible way that we foresee for funding them is through the EC. A potential alternative, currently being planned, is a European Research Infrastructure Consortium (ERIC), which would be a mutual collaboration between the Member States. The mechanism for setting up the ERIC is rather heavy, and it must be ensured that its focus on research use of the data will not undermine the usability of the data for health monitoring and health policy decision making. It is also possible, in principle, that the countries fund
directly many of the activities such as the consultation visits, site visits and external quality assessment for their surveys. The main concern of this alternative is that some of the actions, such as updating of the EHES Manuals and related training materials would not receive funding and the services would not be used by the countries for which they would be most important. This would also make it rather difficult to maintain the required expertise within the EHES Coordinating Centre.

In addition to health monitoring, national HES data has had, and will have, an important role in epidemiologic and public health research to identify potential risk factors for key public health problems. In many of the previous and ongoing national HESs, some of the collected biological samples such as blood, urine or DNA, have been stored for future use in biobanks.

The value of HES data for research has increased substantially by the possibility to link HES data with administrative registers in many countries. A common example is the linkage of HES data with causes of death registers, and increasingly also with hospital discharge registers, outpatient registers and drug prescription registers. The possibility to link HES data and biobanks with administrative registers has made HES data a part of the Big Data, which has a major potential for health information and research.
References


