## HEIDI health wiki

# Sharing, comparing and developing health information across Europe

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In 2010, the European Commission launched a new tool for gathering and updating European health information: web-based wiki HEIDI¹ was presented to the public for the first time in the European Health Forum in Gastein.

HEIDI is an attempt by the Commission's Directorate-General for Health and Consumers to respond to needs of health information users for up-to-date, reliable and easily usable EU-level data. Unlike printed reports that go out of date more and more quickly, the wiki model provides an opportunity to use expert knowledge that exists in Europe to make the latest data available without too much red tape.

HEIDI is based on MediaWiki, a popular free webbased wiki software application developed by and used on all projects of the Wikimedia Foundation (e.g. Wikipedia), as well as on many other wiki websites worldwide. As a dynamic platform, the wiki enables users to correct or adjust existing information quickly and give feedback of its usefulness.

The HEIDI wiki currently contains articles related to health status, diseases, **determinants**, socio-demographic factors, healthcare and health systems, also

discussing policy and institutional aspects. The content is based on results from two projects co-financed by the EU's Health Programme 2003-20082: EUPHIX (European Public Health Information, Knowledge and Data Management System, lead by the National Institute for Public Health and the Environment RIVM of the Netherlands) and the Eugloreh report (Global Report on the Health of the European Union, lead by the Italian Ministry of Health). EUPHIX developed a webbased knowledge system for health professionals and policy makers, presenting structured European public health information and giving a special insight into similarities and differences between EU Member States. The Eugloreh project benefited from the collaboration of health authorities or institutions from all EU Member States, Croatia, Turkey, Iceland and Norway and of major intergovernmental, international and European organisations and agencies. Due to its breadth in terms of coverage of the public health field - consisting of more than 3,000 pages - and in order to continue the life span of this comprehensive report, the Commission decided to transfer the material from printed book format into electronic wiki environment.

### Abstract

DAS GESUNDHEITS-WIKI HEIDI – AUSTAUSCH, VERGLEICH UND AUFBEREITUNG VON GESUNDHEITSINFORMATIONEN FÜR GANZ EUROPA Die Europäische Kommission startete 2010 das internetgestützte Wiki HEIDI (Health in Europe: Information and Data Interface) zum Erfassen und Aktualisieren europäischer Gesundheitsinformationen. HEIDI ist ein Suchwerkzeug, das umfassende Artikel zu Themen aus den Bereichen Gesundheitszustand, Krankheiten, Determinanten, soziodemografische Faktoren sowie Gesundheitswesen und -systeme enthält, wobei auch politische und institutionelle Aspekte behandelt werden.

Dieses Wiki ist für alle Internetuser frei zugänglich, das Erstellen und Bearbeiten von Artikeln ist jedoch, um die Zuverlässigkeit und das hohe wissenschaftliche Qualitätsniveau der Artikel sicherzustellen, europäischen Gesundheitsexperten sowie Behörden, Agenturen und Institutionen vorbehalten. Ziel von HEIDI ist es, allen Interessierten aus ganz Europa vergleichbare, aktuelle Informationen zum Thema Gesundheit zu bieten. Für Gesundheitsexperten in ganz Europa ist HEIDI ein Instrument zum Austauschen, Vergleichen und Aufbereiten von Informationen. Als dynamische Plattform ermöglicht es HEIDI den Benutzern, bestehende Informationen rasch zu korrigieren oder anzupassen und Feedback bezüglich deren Nützlichkeit zu geben.

HEIDI befindet sich noch in der Testphase, d. h. das System ist zwar online, aber um es leserfreundlicher zu gestalten, werden laufend Inhalte bearbeitet und neu strukturiert. Ende 2011 soll das Wiki dann in Vollbetrieb gehen.

Die ersten Inhalte des HEIDI-Wiki beruhten auf den Ergebnissen von zwei Projekten, die von der Kommission im Rahmen des EU-Programms für öffentliche Gesundheit 2003–2008 unterstützt wurden: auf dem Eugloreh-Bericht (»Global Report on the Health of the European Union«, unter Federführung des italienischen Gesundheitsministeriums) und EUPHIX, einer internetgestützten Wissensbasis für Fachleute und politische Entscheidungsträger im Gesundheitswesen (unter Federführung des niederländischen Instituts für Gesundheit und Umwelt RIVM).

Die Kommission freut sich während der Testphase über Kommentare und Anregungen zur Verbesserung des Wikis:

http://ec.europa.eu/health/heidi.

Die in diesem Artikel geäußerten Ansichten des Autors geben nicht unbedingt den offiziellen Standpunkt der Europäischen Kommission wieder.

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HEIDI focuses on scientific and validated data for expert use

Due to this heritage, HEIDI wiki, although technically fully operational, still needs further editing and restructuring to make it more reader-friendly and suitable for web use. The beta/test phase is planned to continue until the end of 2011, after which HEIDI should be in full implementation.

Following the principle of providing open and free access to internet information sources set up by the Commission, the HEIDI wiki is accessible for everyone to read and browse. Editing of the articles contained in the wiki, however, is not allowed without prior authorisation given by the Commission. In order to maintain the reliability and high scientific quality of the articles, editors will need to be able to demonstrate their expertise on their field at EU level and be independent of industry, commercial and business or other conflicting interests. As is customary with wiki tools in general, HEIDI will therefore to a degree rely on the integrity and peer control of the editors to maintain the accuracy of data.

Although the wiki is available for everyone with access to internet, it is likely that due to the specialised nature of information, it will not become a primary search tool for general public. HEIDI does not aim to provide medical or lifestyle advice to people, but focuses on scientific and validated data for expert use, for example on cancer incidence in Europe. Therefore the most relevant user groups are expected to be people with prior knowledge about public health, such as public health experts, researchers and students, officials working for national or sub-national authorities and other specialised audiences, for example civil society organisations or health journalists.

To become editors in HEIDI, users are asked to submit an application to the Commission via the website, together with a CV and list of publications. The data will be handled in conformity with the European data protection rules<sup>3</sup>. In the aim of making HEIDI as open and transparent as possible, the names of editors will be publicly available on the wiki. The editors can also choose to set up their own pages, on which they can post further information about themselves. They can also use discussion pages as a forum for exchange and views outside the actual content of HEIDI.

The ultimate aim is that a broad and diverse pool of editors would over time enrich the content of the wiki and keep it up-to-date with their input. This reliance

on external experts as content providers sets HEIDI apart from other electronic health information sources of DG Health and Consumers, such as the Public Health website<sup>4</sup> or the EU Public Health Portal<sup>5</sup>. The DG Health and Consumers website is the main EU-level route for health information originating from or authored by the Commission, whereas the core function of the Health Portal is to provide links to other relevant public health websites in the EU. Although health reports, indicators and other health information produced by the Commission will be available in HEIDI, the aim of the wiki is to become a wider source of information which is not limited to the Commission's activities.

#### EU ADDED VALUE

In general, the aim of health information work at EU level is to provide information and analysis for evidence-based development, implementation and evaluation of action for health in the European Union, at both EU level and within the EU Member States. An important part of the evidence-based policies is not only the collection of data, but also making information available for those who need it, and analysing the impacts of policies.

European health information can enable comparisons in particular, which can in turn support identification, dissemination and application of best practice. This reflects the mandate for EU action on health set out in Article 168 of the Treaty on the Functioning of the European Union<sup>6</sup>: "Union action, which shall com-

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plement national policies, shall be directed towards improving public health, preventing physical and mental illness and diseases, and obviating sources of danger to physical and mental health. Such action shall cover [...] health information and education [...].

The Commission may, in close contact with the Member States, take any useful initiative to promote such coordination, in particular initiatives aiming at the establishment of guidelines and indicators, the organisation of exchange of best practice [...].

Action on health information is part of the overall health strategy<sup>7</sup> set out by the Commission and endorsed by the Parliament and the Council: »[....] health policy must be based on the best scientific evidence derived from sound data and information, and relevant research. The Commission is in a unique position to assemble comparable data from the Member States and regions and must answer calls for better information and more transparent policymaking, including through a system of indicators covering all levels (national and subnational).«

Ideally, for health-related information to be useful at European level, it should be collected on a harmonised basis covering all Member States. But due to cultural, technical, political and social factors, definitions and measurement of key indicators and data coverage vary across countries. Although cross-country comparisons should be interpreted with some caution, information which is more geographically limited or less harmonised can nevertheless still be useful.

The added value of HEIDI lies in this potential of becoming a central repository or reference point of EU level information, where comparisons, analysis, and exchanges across Europe are possible.

#### ONLINE INDICATORS AT EU LEVEL

Comparable data needs to be based on common indicators, with agreed definitions, collection and use. The Commission has worked for many years in close cooperation with health information experts from EU Member States to establish and agree a set of indicators in order to move towards a sustainable health monitoring system in Europe. As a result of this work the European Community Health Indicators (ECHI)8 were developed, and now provide the core of the European health information work. ECHI is currently a set of over 40 indicators where comparable and reliable information is available covering demographic and socioeconomic factors, health status, determinants of health and health services. The ECHI, as well as other sets of EU level indicators, are available in the HEIDI wiki through an interactive electronic database, HEIDI Data Tool.

The data tool allows for viewing and downloading chosen indicators as well as selecting their geographical coverage, timeline and graphical presentation as a map, graph, or table. This can be useful if, for instance, a national public health institute wishes to present a map on healthy life years in the EU-27 on its website: this map is a dynamic element which will be automatically up-dated on the institute's website every time the source data is up-dated in HEIDI data tool. The data used by the tool comes from EU's statistical office Eurostat, WHO, OECD or projects funded by the EU.

The HEIDI wiki users will also be able to create "my reports" by selecting articles and graphs from the wiki into one single document that can be saved or printed out as a pdf or html file.

#### CONCLUSION

Throughout the test phase of HEIDI, DG Health and Consumers has requested and received valuable input from people who are experts in the field of health information. This cooperation will hopefully not cease when HEIDI is fully operational: the experts will be called upon not only to provide contributions for the wiki, but also to advise the Commission in improving and developing it further. We hope that with their help, HEIDI will find her feet and become a useful tool that will benefit the European public health community.

The views presented are those of the author and do not necessarily represent the official view of the European Commission.

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<sup>1.</sup> Health in Europe: Information and Data Interface. http://ec.europa.eu/health/heidi

<sup>2.</sup> http://ec.europa.eu/health/programme/policy/index\_en.htm

Regulation (EC) No 45/2001 of the European Parliament and the Council. the protection
of individuals with regard to the processing of personal data by the Community institutions
and bodies and on the free movement of such data. 18.12.2000

<sup>4.</sup> http://ec.europa.eu/health/index\_en.htm

<sup>5.</sup> http://ec.europa.eu/health-eu

<sup>6.</sup> http://eur-lex.europa.eu/JOHtml.do?uri=OJ:C:2010:083:SOM:EN:HTML

White paper.Together for Health. A Strategic Approach for the EU 2008–13', COM(2007)630, 23.10.2007

<sup>8.</sup> http://ec.europa.eu/health/indicators/echi/index en.htm