

EUnetHTA INFORMATION MANAGEMENT SYSTEM: DEVELOPMENT AND LESSONS LEARNED

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Objectives: The aim of this study was to describe the techniques used in achieving consensus on common standards to be implemented in the EUnetHTA Information Management System (IMS); and to describe how interoperability between tools was explored.

Methods: Three face to face meetings were organized to identify and agree on common standards to the development of online tools. Two tools were created to demonstrate the added value of implementing interoperability standards at local levels. Developers of tools outside EUnetHTA were identified and contacted.

Results: Four common standards have been agreed on by consensus; and consequently all EUnetHTA tools have been modified or designed accordingly. RDF Site Summary (RSS) has demonstrated a good potential to support rapid dissemination of HTA information. Contacts outside EUnetHTA resulted in direct collaboration (HTA glossary, HTAi Vortal), evaluation of options for interoperability between tools (CRD HTA database) or a formal framework to prepare cooperation on concrete projects (INAHTA projects database).

Conclusions: While being entitled a project on IT infrastructure, the work program was also about people. When having to agree on complex topics, fostering a cohesive group dynamic and hosting face to face meetings brings added value and enhances understanding between partners. The adoption of widespread standards enhanced the homogeneity of the EUnetHTA tools and should thus contribute to their wider use, therefore, to the general objective of EUnetHTA. The initiatives on interoperability of systems need to be developed further to support a general interoperable information system that could benefit the whole HTA community.

Keywords: Information systems, International collaboration, EUnetHTA

The European network for health technology assessment (EUnetHTA) was founded in 2006 with strategic objectives to promote more effective use of resources, increase HTA input to decision making, strengthen the link between HTA and policy making, and support countries with limited experience in conducting HTAs (1). Since 2009, EUnetHTA partners have had access to four Web sites or online databases (also referred to as “tools”) created during the EUnetHTA Project period (2006–08): the Members-only site (MO site), the Planned and Ongoing Projects Database (POP DB) (2), the HTA Core Model® online, and the EVIDENT database (formerly known as EIFFEL) (3). These tools were developed independently, without specific coordination or vision concerning interoperability. This resulted in tools with a different layout, vocabulary to index content and login systems which raised some complaints amongst end users.

Between 2010 and 2012, the work of EUnetHTA was organized into eight work packages (WPs) and financially

supported by the Health Program of the Executive Agency for Health and Consumer of the European Commission Joint Action (JA) program (see the EUnetHTA Web site for more details) (4). The activity “Work package 6 - Information Management System” (WP6), led by the Belgian Health Care Knowledge Centre (KCE), brought together seventeen partners from fifteen countries (see list of partners in Table 1). The main objective of this work package was to provide a contemporary Information Management System (IMS) within EUnetHTA, ensuring compatibility and interoperability of tools across work packages to facilitate collaborative HTA work, and rapid dissemination of HTA results to all EUnetHTA partners (see list of tools in Table 2). The activities of WP6 were defined in a 3-year work plan and included: (i) further development of tools created during the 2006–08 period to enhance homogeneity and facilitate their usage by end users; (ii) development of new tools, including demonstrators of well-established standards that could support the general objective of rapid dissemination of HTA results; and (iii) identification of already existing tools developed outside of EUnetHTA to avoid duplication of efforts, and evaluate opportunities of collaboration.

The objectives of this article are to describe: (i) how WP6 group was created and managed to facilitate the identification and agreement on common standards for EUnetHTA tools; (ii) how interoperability standards could be demonstrated; (iii) the

The authors thank all the participants to EUnetHTA Joint Action Work Package 6 for their invaluable input; CRD York, HTAi IRG and INAHTA for welcoming options to collaborate; Irina Cleemput, Kirsten Holdt Henningsen, Laurence Kohn, and Lorena San Miguel for helping us in the text preparation.

EUnetHTA Joint Action was supported by a grant from the European Commission, Agreement number 2009 23 02. The sole responsibility of this article lies with the author(s) and neither the Commission nor EUnetHTA is responsible for any use that may be made of the information contained therein.

Table 1. Partners of the EUnetHTA Work Package 6 Information Management System (2010–2012)

Country	Full name (English translation)	Acronym	Role
Belgium	Federaal Kenniscentrum voor de Gezondheidszorg – Centre fédéral d'expertise des soins de santé (Belgian Health Care Knowledge Centre)	KCE	Lead Partner
Germany	Deutsches Institut für Medizinische Dokumentation und Information (German Institute for Medical Documentation and Information)	DIMDI	Co-Lead Partner
Austria	Gesundheit Österreich GmbH	BIQG/GÖG	Associated Partner
Austria	Hauptverband der Österreichischen Sozialversicherungsträger (Association of Austrian Social Insurance Institutions)	HVB	Associated Partner
Austria	Ludwig Boltzmann Institute for Health Technology Assessment	LBI-HTA	Associated Partner
Finland	Terveyden ja hyvinvoinnin laitoksen (National Institute for Health and Welfare National Institute for Health and Welfare)	THL	Associated Partner
France	Haute Autorité de Santé (French National Authority for Health)	HAS	Associated Partner
Hungary	Gyógyszerészeti és Egészségügyi Minőség- és Szervezetfejlesztési Intézet (National Institute for Quality and Organizational Development in Healthcare and Medicines)*	GYEMSZI	Associated Partner
Netherlands	College voor Zorgverzekeringen	CVZ	Associated Partner
Slovenia	Nacionalni Inštitut za javno zdravje (National Institute of Public Health of the Republic of Slovenia)	NIJZ	Associated Partner
Spain	Instituto De Salud Carlos III	ISC III	Associated Partner
Sweden	Statens beredning för medicinsk utvärdering (Swedish Council on Technology Assessment in Health Care)	SBU	Associated Partner
United Kingdom	NIHR, Evaluation, Trials and Studies Coordinating Centre	NETSCC	Associated Partner
Italy	Agenzia Regionale per i Servizi Sanitari (Piemonte)***	AReSS	Collaborating Partner
Spain	Osteba, Servicio de Evaluación de Tecnologías Sanitaria (Basque Agency for HTA, Department of Health)	OSTEBA	Collaborating Partner
Turkey	Kanıt Dayalı Tıp Derneği (Turkish Evidence-Based Medicine Association)	KDTD	Collaborating Partner
Switzerland	Swiss Network for Health Technology Assessment	SNHTA	Collaborating Partner

*Merge of ESKI and EMKI.

**Now Zorginstituut Nederland (National Health Care Institute) –ZIN.

***AReSS has ceased its activities in 2013.

Table 2. EUnetHTA Tools of the EUnetHTA Information Management System (2010–2012)

Tool (URL)	Description	Maintainer(s)	Access
Adaptation Glossary online (http://glossary.eunethta.eu/)	Publish descriptions of terms provided by several Partners, helping to identify how the usage of terms may differ between countries	NETSCC, KCE	Public access
Evidence database on new technologies (EVIDENT DB) (http://evident.eunethta.eu/)	Store information on reimbursement/coverage status of technologies and on requested additional studies (under development or implemented)	HAS	Access restricted to EUnetHTA partners
HTA Core Model® Online (http://htacore.eunethta.eu/)	Facilitates the production of HTA information using the HTA Core Model®	THL	Plenty of content is freely available use of the tool to produce HTA information regulated by a license
Members only site (MO site) (http://intranet.eunethta.eu/)	Provides contact database, news, documents, and working group areas	KCE	Access restricted to EUnetHTA partners
News Aggregator (http://aggregator.eunethta.eu/)	Automatically aggregate and tag RSS feeds from several EUnetHTA Partners Web sites	KCE	Public access
Planned and Ongoing Projects database (POP DB) (http://popdb.eunethta.eu/)	Store descriptions of planned or ongoing projects from EUnetHTA Partners	LBI-HTA, DIMDI	Access restricted to EUnetHTA partners providing content
Repositories Aggregator (Closed)	Automatically aggregates documents descriptions from institutional repositories of EUnetHTA Partners	KCE	/

status of collaboration with information systems outside EUnetHTA reached at the end of the 3-year period.

METHODS

Agreement on Common Standards

A mixed group was created by the EUnetHTA Joint Action work package 6 coordinator: one representative of each EUnetHTA tool team (HAS for EVIDENT DB, LBI-HTA for POP DB, NETSCC for Adaptation Glossary, THL for HTA Core Model[®] online) and (potential) users of the tools were invited to take part in WP6. Four face to face meetings were planned (two in year 1, one in year 2, and one in year 3); organisation and participation (travel, hotel) costs linked to those face to face meetings were funded by the Joint Action. To facilitate a sense of belonging to the group and favor participants engagement and communication between technical and nontechnical people, two ice breaking techniques were used at the first face to face meeting in April 2010 as replacement of the traditional round of presentations. Participants were first tagged with Post-its[®] of different colors related to their profile (IT or non-IT), and their experience in EUnetHTA (having previously participated to EUnetHTA or not). Then, three rounds of “speed dating” were organized: at each round, attendees were asked to choose a partner with another profile (to get pairs of IT and non IT); and talk for 3 minutes to exchange information about their respective work. Oral feedback from participants was requested at the end of the exercise, and during the last face to face meeting at the end of the 3-year period and summarized in the meeting minutes. Potentially interesting “standards” were identified by WP6 lead (KCE) and co-lead (DIMDI) by searching the Web, the literature, or by consulting colleagues. A synthesis document was prepared to support group discussions. Partners met face to face three times to discuss and agree on common standards for the development of the tools. Agreement was reached by consensus (see [Table 3](#)); implementation was under the responsibility of the respective work packages (WP4 for HTA Core Model[®] Online; WP6 for POP DB, Adaptation glossary online, Aggregators; WP7 for EVIDENT DB).

Demonstration of Interoperability Standards

Among the tools developed as part of WP6, two Web sites aimed at demonstrating widespread interoperability standards: the “Repositories aggregator” for the Open Archives Initiative Protocol for Metadata Harvesting (OAI-PMH) protocol, and the “News aggregator” for the RDF Site Summary (RSS) protocol. Sources to aggregate were identified by searching the partners’ Web sites, dedicated repertories, and by direct contact with colleagues. The “aggregator” Web sites were presented or demonstrated within WP6, at other EUnetHTA Work Package meetings, and also to a broader audience (e.g., EUnetHTA Conference, HTAi Conference).

Collaboration with Information Systems Outside EUnetHTA

Tools already in use outside EUnetHTA were identified by searching the Web, the literature, scientific procedures, and by consulting colleagues. The developers identified through this process were subsequently contacted by e-mail to explore opportunities for collaboration; and in some cases, phone conferences or face to face meetings were organized.

RESULTS

Agreement on Common Standards

The first face to face meeting was held in April 2010. It brought together eighteen people from thirteen Partner’s organisation. Among them, thirteen tagged themselves as new to EUnetHTA; ten as content specialists, five as IT specialists, and three as having both profiles. The first feedback, provided after the ice breaking session, was positive: participants reported that the speed dating exercise facilitated the exchange of relevant information about their respective activities, responsibilities and about EUnetHTA in a fast and humorous way. At the end of the 3-year period, participants reported that the group had benefited from a positive atmosphere; the ice breaking techniques conducted at the first face to face meeting and the role of the group moderator were reported as supporting factors. This good atmosphere was identified as an important element that helped each type of participant to present their specific perspective (developer versus user), and nontechnicians to ask for “translation” of technical concepts and “jargon” into mainstream terms to facilitate a better understanding (e.g., Single Sign On). Exchanges were also considered very fruitful for both types of participants: developers gained better insights on the needs of the users regarding IT tools, while users gathered a better view of some of the most common constraints encountered when developing IT tools. Four common standards types that tool developers should comply with were identified and agreed upon: metadata, layout, vocabulary and authentication (see [Table 3](#)). Subsequently these were described in a guidance document (5). The Metadata Terms from the Dublin Core Metadata Initiative (6) were selected as a reference to organize the content of records and label their fields. When the Dublin Core did not fulfill the needs, additional metadata can be chosen, preferably from an existing metadata scheme already endorsed at the European level to be found at the SEMIC Web site (7). A common layout for EUnetHTA tools was defined based on the initial EUnetHTA public site (2006–08) and the EUnetHTA graphical guidance (8). This common layout includes a two-column structure with headers and footers. While standard components are defined for each area, several alternatives are provided for developers to suit the specific objectives of their respective tools. Partners agreed on that the Medical Subject Headings (MeSH[©]) (9) was the best suited vocabulary to describe topics of records. Where relevant, several fields can be provided (e.g., one field

Table 3. Standards Selected by WP6

Name	Description	Type	Status
Dublin Core meta data (DC)	Metadata set to describe Web or physical resources	Common meta data	Agreed as Common standard
EUnetHTA common layout	Guidelines to design EUnetHTA Web sites hosting tools	Common layout	Agreed as Common standard
Medical Subject Headings (MeSH)	National Library of Medicine's controlled vocabulary thesaurus used for indexing articles from biomedical journals for the MEDLINE®/PubMed® database	Common vocabulary	Agreed as Common standard (mandatory)
Anatomical Therapeutic Chemical (ATC) classification	Classification of substance aiming at standardising drug utilization studies	Common vocabulary	Agreed as Common standard (optional)
International Classification of Diseases (ICD)	Classification of diseases for epidemiology, health management and clinical purposes	Common vocabulary	Agreed as Common standard (optional)
Lightweight Directory Access Protocol (LDAP)	Application protocol for accessing and maintaining distributed directory information services over an Internet Protocol (IP) network	Unique Authentication	Agreed as Common standard
RDF Site Summary (RSS)	XML format for publishing frequently updated information	Interoperability standard	Included in a demonstrator
Open Archives Initiative Protocol for Metadata Harvesting (OAI-PMH)	Application-independent interoperability framework used to harvest (or collect) the descriptions of records in an archive or an institutional repository	Interoperability standard	Included in a demonstrator

for the problem and one field for the intervention, respectively P and I from the PICO clinical question) (10). A link to the MeSH© database and the HON Select (11) which offers a free access to MeSH in several languages is recommended to help users to identify the appropriate term to search content from the EUnetHTA tools. While covering all the necessary domains, MeSH© was not universally used in other information systems of the participating countries. Therefore, developers were free to implement any supplemental vocabulary that would fit the needs of their tools (e.g., ATC codification, ICD-10 classification). The Lightweight Directory Access Protocol (LDAP) (12) was selected as common standard for authentication based on its wide use and opportunities for rapid implementation. It allow users to access the different EUnetHTA tools with the same login details, called EUnetHTA ID. The Members Only site was used as a source of credentials for all tools. By the end of the 3-year period, all tools were modified or designed following the common standards previously described.

Demonstration of Interoperability Standards

The “Repositories Aggregator” demonstrator was delivered at the end of 2010. This tool was automatically aggregating the two institutional repositories available at the time of development: LBI-HTA (Austria) and KCE (Belgium). Visitors could thus browse or search the aggregated catalogue and get access to the full text of reports hosted at the source repository. Because no new repository could be identified at the end of the 3-year period; it was decided to close it down because of incompleteness. The second demonstrator, the “News aggregator”, was delivered in 2011. Initially, nine RSS feeds were included (three coming

directly from the partner's Web site, six being created by a third party online service). Each RSS item was transformed into a Web page being automatically categorized by country, partner and language. The availability of RSS feeds was regularly revised, with twenty-two available in 2012 (of which ten were obtained through a third party online service); while thirteen partners' Web sites still did not provided any RSS feeds. By the end of 2012, the News aggregator had received an annual average of approximately 1,000 unique visitors. From January 2014, visitors can browse or search within more than 10,000 aggregated news.

Collaboration with Information Systems Outside EUnetHTA

Additionally, four HTA tools developed outside EUnetHTA but of potential interest for EUnetHTA activities were identified. Their developers were contacted to evaluate options to collaborate. Contacts resulted in (i) direct collaboration (HTA glossary, HTAi Vortal), (ii) evaluation of options for interoperability between tools (CRD HTA database), or (iii) formal framework to prepare cooperation on concrete projects (INAHTA projects database) (see Table 4).

DISCUSSION

Projects bringing together people from a large variety of cultural and professional backgrounds, and making use of electronic meetings have been shown to be challenging in several contexts including Community of Practice initiatives and e-learning (13;14). In such contexts, face to face interactions are often highly valued (15); and ice breaking activities are recommended in situations where a group of people who never met

Table 4. HTA Tools Developed Outside EUnetHTA and the Related Collaboration Status

Tool (URL)	Description	Maintainer(s)	Collaboration status
HTA Database (http://www.crd.york.ac.uk/CRDWeb/)	Provides description of ongoing HTA projects and published HTA reports	CRD, University of York (UK)	A Meeting occurred between CRD team and WP6 Lead Partner, options to exchange data have been investigated. Concrete application is to be established
HTA Glossary (http://htaglossary.net/)	Provides definitions of terms, in English, French and Spanish (German in preparation)	HTAi / INAHTA	WP6 Lead Partner represents EUnetHTA at the International Steering Committee
HTAi vortal (http://vortal.htai.org/)	Provides description of HTA web resources	HTAi Information Resource Group (IRG)	WP6 Lead Partner is part of the editorial team and participated to the renewal of the technical infrastructure
INAHTA Projects database (http://www.inahta.org/)	Store description of planned and ongoing projects from International Network of Agencies for Health Technology Assessment (INAHTA) members	INAHTA	A memorandum of understanding between INAHTA and EUnetHTA has been signed in 2012, cooperation is to be initiated

will have to interact (14;16). The group of WP6 partners' representatives was indeed heterogeneous and, being geographically dispersed, it could even be considered as primary "virtual" (17). Meeting face to face and including an ice breaking session at the first meeting were perceived as important factors for establishing the positive group atmosphere reported in the feedback. Still, further evaluation would be necessary to explore to which extend those two approaches influenced the group atmosphere.

Discussions over common standards raised doubt about the ability of MeSH© to perfectly describe the content. Furthermore, some participants reported that those in charge of content provision lack familiarity with MeSH©. Although these two issues are quite common when using MeSH; this has proven to be adequate in several circumstances (18–20), and the provision of support and training usually helps people to better perform in indexing information (21). Nevertheless, further investigation would be needed to evaluate the MeSH© implementation into each tool and the support provided to encoders.

With Joint Action 1, EUnetHTA left the pioneering period for a stabilization period. This is also reflected by the evolution of its Information Management System: thanks to WP6 activities, all tools now look more similar and familiar to the end users (same layout, same vocabulary, similar meta data), and can be accessed by means of a single login system. All this should benefit the end user by providing more efficiency and memorability (as defined by Nielsen (22)), and thus enhancing satisfaction. While such an assumption has not been directly tested, it is generally supported by the results of the general surveys conducted once a year where 60 percent of respondents found single authentication useful or very useful, and where barriers to the use of tools related to tools themselves diminished over time (23). Other international collaborations networks like the Cochrane

Collaboration face similar challenges; and foresee similar approaches: users will be at the centre of tool developments in the forthcoming years, and interoperability between the different software is planned to be developed thanks to a new concept of information architecture (24).

Despite the interest shown during discussions regarding the added value of OAI-PMH (25), the Repositories Aggregator was shut down in 2012. Barriers to implement an institutional repository are known to be human rather than technical (26). Adapting the current publication flow, and providing the necessary supporting IT infrastructure are indeed challenges difficult to overcome in such short time period. Searching the HTA database and the Web site of agencies (possibly through the HTAi Vortal) will thus probably remain the standard at many agencies (27;28) until some technical evolution offers new opportunities in the coming years (e.g., Web Content Management Systems used for the Web sites of partners being compliant to OAI-PMH or any other data linkage standard). Regarding RSS, while several Web sites do not directly provide RSS feeds, we can expect that the status will positively evolve because a majority of them are driven by Web Content Management Systems that offer such an option. Asking partners to activate this feature and provide a specific RSS feed for published reports is, therefore, currently considered to be a good option to support rapid dissemination of this information through a RSS aggregator. Additionally, this would offer the opportunity to disseminate the same information through other channels like widgets, social networks, browser toolbars, and mobile applications. The monitoring of partners' Web sites and the development of the Aggregator will thus be pursued.

While collaboration was always positively perceived by maintainers of tools developed outside the EUnetHTA IMS,

technical developments would require additional resources. The integration of interoperability standards in the respective development roadmap of tools should be the first step on the way to interoperability.

CONCLUSIONS

While being entitled a project on IT infrastructure, the EUnetHTA Work Package 6 “Information Management System” was also about people. On the one hand, we had participants with different backgrounds and experiences. The three years’ experience showed that when having to agree on complex topics, fostering a cohesive group dynamic and hosting face to face meetings brings added value and enhances understanding between partners. On the other hand, we had the end user of the tools. The adoption of widespread standards should help to provide a sense of “feeling at home” when using any of the EUnetHTA tools. For example, a single login facilitates access to the tools which should in turn enhance their use, and, therefore, contribute to the general objective of EUnetHTA.

Finally, WP6 also puts in place the basis for data linkage between EUnetHTA tools and tools developed outside EUnetHTA. For this linkage to happen, a clear and official mandate and appropriate funding, like the Joint Action mechanism, is essential when interoperability is expected to come into place in a short term. Without such a support, the coordination of development is more complex, even when all parties are willing to enhance global efficiency and reduce duplication of efforts. Still, interoperability between EUnetHTA tools and others could be achieved if expectations on the timing of implementation are adjusted. The initiatives on interoperability of systems started in the first Joint Action period will be developed further in the second Joint Action period (2012–15); and, we hope, will result in a general interoperable information system that goes beyond EUnetHTA to serve the whole HTA community.

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CONFLICTS OF INTEREST

Both authors report grants to their institutions from the European Union.

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