

PROJECT FINAL REPORT

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4.1 Final Publishable Summary Report

Executive Summary

Europe's health systems are struggling with providing accessible, equitable high-standard of care while restraining the costs of health services. Underperforming care and overexposure to health services are therefore important challenges to meet. In order to make the right decisions policy makers, health managers and professionals need to count on the right information.

The basis for providing optimum health services lays onto in depth monitoring and analysis of the equitable access, quality and efficiency patterns in our health systems from a multilevel perspective. Thus, the key task facing the interdisciplinary team of doctors, statisticians, economists and information technology officers enrolled in the ECHO project is to refine a comprehensive set of performance indicators to enable the identification of possible deficits (unwarranted variations in health care performance) in the health systems, and to provide evidence to inform policy and management decisions.

The ECHO project, co-financed by the European Commission, is designed to create a "knowledge" system. At the core of this knowledge system is the development and implementation of a common data warehouse and a series of on-line tools allowing users to explore equitable access, quality and efficiency of healthcare at the hospital, healthcare area, regional and country level. Noticeably, the ECHO tool, an analytical device that will be accessible to pre-registered research scientists and policy makers via website. This online analysis tool is scheduled to be operational for EU stakeholders during the 2nd half of 2014. Finally, methods underpinning ECHO findings and developments will be also available on-line.

ECHO has focused on developing a robust methodology to compare performance across healthcare systems – 1) building valid crosswalks across coding languages in up to 50 performance indicators; 2) creating benchmarks to allow sound international comparison; 3) building maps where national vectors have been gathered for depicting the maps of each country taking into account the meaningful areas relevant for each country. ECHO performance Atlases used this methodology to report unwarranted differences in health systems performance across ECHO countries. Atlas reports on cardiovascular care, lower value care and potentially avoidable admissions have been yielded. These reports feature international and in-country variations in performance, its evolution over-time, the effect of socioeconomic gradient, and provide some policy messages derived from the results.

However, ECHO is a starting community. The strength of ECHO as a routine tool for EU decision-makers will become a reality if ECHO is able to provide: 1) the most up-to-date information (ECHO pilot was based on 2002 to 2009 info); 2) a larger case-mix of countries (namely, healthcare systems) enabling more reliable benchmarking; and 3) a strong critical mass supporting a sustainable and growing research infrastructure that regularly yields robust evidence.

The above raises a set of unique challenges. It is overcoming the above challenges that ECHO is concentrated on. To know more, visit the project website at www.echo-health.eu

Context & Objectives

The context

In the last two or three decades research on health systems and policy research has provided numerous evidence on healthcare performance that could be translated into policy messages such as: a) the place where a person lives determines the exposure to high value or low value care; b) more care is not always better; c) healthcare organizations produced uneven health outcomes, once differences in patients are ruled out; d) learning cascades are determinant in attaining good health outcomes but also, might hold substandard performance; e) access to effective ambulatory care improve health outcomes; f) money does not always become value; g) access to effective and safe healthcare may be determined by socioeconomic status; h) high-quality information may reduce allocative inefficiency; i) populations are facing high opportunity costs associated to the exposure to low value care.; or j) continuity of care is critical in attaining better outcomes in chronic patients .

The European Commission, throughout EU research programmes, has funded many research projects meant to shed light on either rethinking performance or studying how systems perform. [<http://www.healthdatanavigator.eu/international-home/eu-and-international-projects>]

However, even though some National Agencies have been either producers or early adopters of some of those research findings, the uptake of evidence is still scarce and unequal across EU Member States.

Many reasons have been suggested: 1) lack of consensus on what health systems performance is; 2) the inherent difficulties on implementing findings that are usually coming from different contexts; 3) the lack of trust on data; 4) the absence of a common agenda between research and policy-making; 5) the scarcity of research infrastructures that allow international comparison; 6) the need of comparable performance indicators and common benchmarks for comparison; 7) the secular inability of researchers to improve public reporting; or 8) the limited and uneven critical mass on health services and policy research in Europe as compared to USA, for example.

The objectives

The ECHO project, has addressed some of those hindrances.

ECHO (2010-2014), a collaborative project funded by the EC 7th Framework program, was conceived as a demonstration project on healthcare performance assessment, set about the task of bringing together patient-level routinely collected data from Austria, Denmark, England, Portugal, Slovenia and Spain.

From the point of view of the healthcare performance assessment debate, ECHO expanded the usual approach on international comparison based on average figures (i.e. scarcely informative), based on measures uncertainly comparable (i.e. dubious acceptance), and unable to provide reliable benchmarks (i.e. with limited capacity for leveraging any policy decisions). Conversely, ECHO has been able to analyse performance variation within and across countries at different decision-making levels (i.e. able to inform policy-decision), using comparable measures (i.e. increasing reliance on data), and developing accurate benchmarks (i.e. enabling decision making).

Some instruments were critical in attaining those goals:

- 1) The construction of a single accessible knowledge infrastructure where multiple datasets from five ECHO countries (up 30 information sources) were harmonized, stored and made accessible for research.
- 2) The development of around 50 healthcare performance indicators comparable across 5 countries, entailing: the production of a common framework for healthcare performance assessment, a conceptual agreement on the definition for each one of those, the elaboration of a map of codes matching the definition, and the face- and empirical validations of those definitions within each country.
- 3) The use of tailored benchmarks built on data pooling and using sound and robust statistical techniques. Thus, allowing in-country, cross-country and “aspirational” benchmarking.
- 4) The inclusion of local stakeholders in the face- and empirical validation process of the performance indicators, and in the dissemination of the in-country performance results.

S&T Results

As outlined hereafter, key ECHO Scientific and Technology contributions involve a number of research areas, from architectural framework for the ECHO Data Warehouse (DWH) to software unique developments for the ECHO Tool. Here, main Scientific and technological outputs are briefly described.

Measuring the performance of European health systems in a comparable and quantifiable way represents a major challenge. Reliability in the ECHO project is being ensured through a set of cutting-edge methodological developments laying the technical foundations of the project:

1. The ECHO DWH has been successfully consolidated (4th version) containing information from the six countries involved in ECHO, following the foreseen logic data model.
2. That version has been exposed to a large and systematic quality checking in order to test its internal coherence, reliability and accuracy; therefore, the logic model and the consistency of the core variables and ECHO indicators over time, and per country have been explored. The results have been collated in the ECHO Information System Quality Report.
3. With the goal of depicting boundaries (natural catchment areas or administratively defined areas) national vectors have been gathered for depicting the maps of each country taking into account the meaningful areas for each country. A Spanish-Danish pilot study was developed to test how size heterogeneity and flows between areas might influence estimates. Based on the empirical analyses, ECHO has decided to add a new map in Portugal, England and Denmark, base upon the actual flows of population seeking care (hospital catchment areas).
4. From a pool of performance indicators that had proven valid for performance assessment purposes at multinational level using administrative data– the ECHO consortium chose around 50 to be analyzed within the ECHO project.
5. Those indicators were defined using national coding systems taking as a reference ICD 9th CM, developing crosswalks across classifications. In order to evaluate the validity of those definitions, face validation and empirical validation were performed. Fact sheets for each indicator and country were built for that purpose. Feedback from country experts was adopted and final definitions implemented before analysis.
6. A handbook including all methodological insight provided by ECHO has been drafted, and will be available on-line.
7. Preliminary results from several of these indicators have been shown in several events; some of them have been already used to inspire policies (SANCO, OECD), some of them have been released in international scientific conferences (iHEA, EUPHA, Wennberg International Collaborative).

8. Additionally, 10 ECHO Local Dissemination Groups, aimed both at validating the ECHO outlets and to discuss uptake and use of project output by different stakeholders, have been organized with a turnout of 160 stakeholders from 5 EU countries.

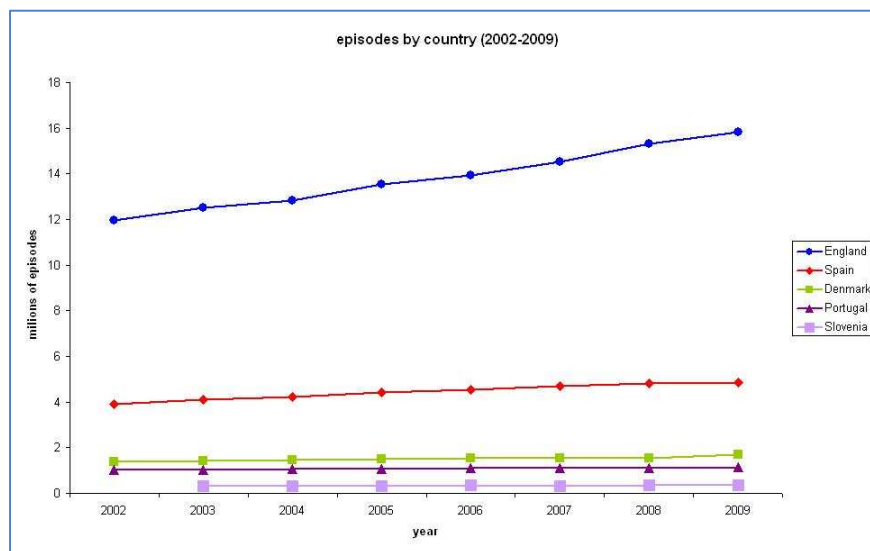
9. Atlas reports on coronary revascularization, lower value care and potentially avoidable admissions have been drafted. These reports feature international and in-country variations in performance, its evolution over-time and the effect of socioeconomic gradient, and provide some policy messages derived from the results.

10. A set of web-based analytical tools has been developed allowing the replication of new analyses, as well as the report of the main results.

ECHO DWH

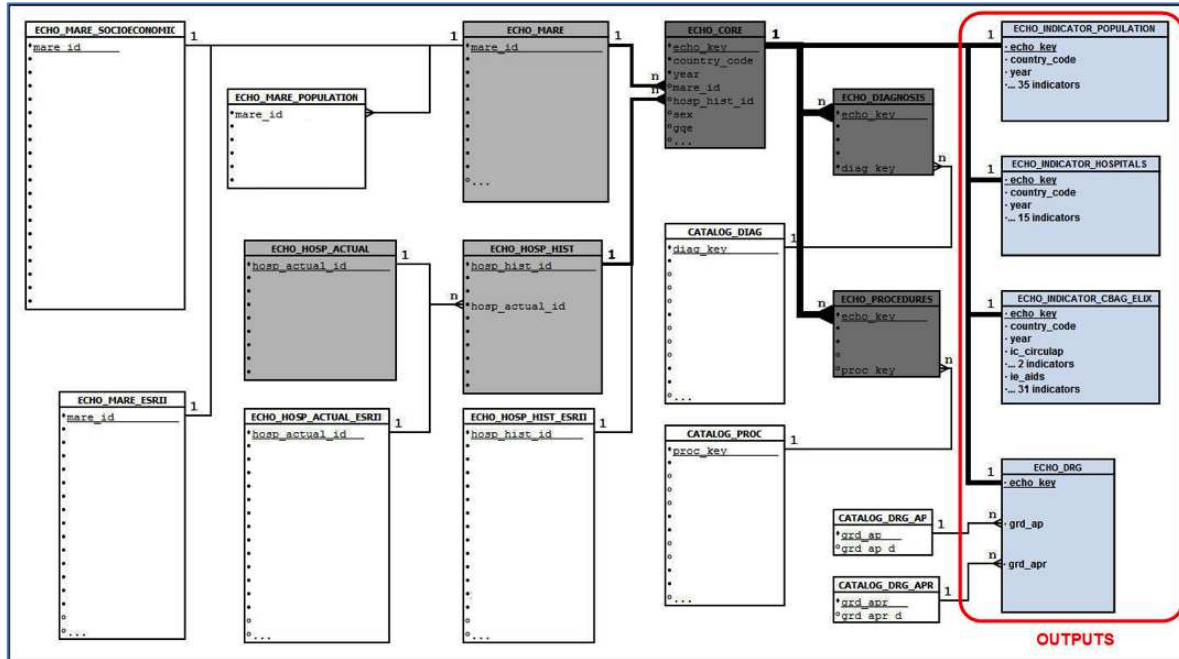
ECHO DWH was designed as a relational database for the storage of information of hospitalization episodes, obtained at discharge. Each registry at the DWH, up to 200 millions, corresponds to a single episode, in which all the attributes (variables) of interest for potential analyses are recorded.

ECHO Episodes contribution by country and year (millions)



Output files development

All the ECHO DWH developments are meant to obtain 4 output files (see figure): geographic indicators file, hospital indicators file, risk-adjusters file, DRG file². While the two first are collecting the ECHO performance indicators, the latter are auxiliary files used in risk adjustment modelling when estimating case-fatality rates, adverse events, or resources consumption.



Collection of national databases & data quality checking

The ECHO-DWH is fed with official statistics, national census and nation-wide administrative registries, collected by top-level government institutions, like Ministries of Health. The ECHO project works primarily with sensible data. Clear transfer responsibilities have been contractually set up with partners, making it clear who was responsible before, during transportation, reception and use of the individual data. To this end, a number of data transfer & data use agreements stating use limitations and/or protection requirements were signed.

ECHO Information system quality report

The consolidated version of the ECHO DWH was exposed to a quality analysis, essentially meant to assess internal coherence (a contrast of identity rules, referential integrity, cardinality and preservation

² DRG (Diagnosis-Related Groups) were just applied to Spain and Portugal since DRGs are based on ICD 9 CM.

of inheritance principles), reliability (a measure of the internal consistency of core elements across countries, and over years) and accuracy (an assessment of potential misclassification biases). The results of this quality analysis have been included in the ECHO Information System Quality Report.

Face- and empirical validation

Face- and empirical validation had as main output the selection of a set of performance indicators sound enough to be used in the performance analysis, in country and cross-country.

The choice of indicators was made on the basis of a valid and reliable comparability across countries and relevance to health care decision makers. At the end of this process a set of around 50 healthcare performance indicators are considered reliable for that purpose.

The validation process consisted of a set of tasks, starting in the previous reporting period with the development of a common framework for healthcare performance assessment, a conceptual agreement on the indicators that match the framework, and the elaboration of definition for each one of those indicators, as well as the map of codes matching the definition. Then, stemming from ICD9th-CM specifications for each ECHO indicator, crosswalks were translated into the different coding classifications in place. ECHO countries used two different systems of diagnosis coding (ICD and ICD10) and four different systems of procedure coding. For each of the indicators, crosswalks from ICD9-CM to the other systems were devised and checked (see table).

Codification of diagnoses and procedures in ECHO countries

| Country | Diagnoses | Procedures |
|----------|------------------------|------------------------|
| Portugal | ICD 9 th CM | ICD-9 th CM |
| Spain | | |
| Denmark | ICD-10 th | NOMESCO |
| England | | OPCS4 |
| Slovenia | | ACHI |

Those crosswalks were implemented into the DWH (version 1) and raw numbers (cases and population at risk) for each indicator and country were calculated and mapped out. These figures compose the basic material for validation – essentially an in-country *prima facie* acceptance of the definitions for each indicator and the corresponding results. In country experts and stakeholders were asked to double-check the definitions with local coding practices and, numbers and figures with local information sources, and to point out those oddities that deserved further attention –looking deeper into the codes, crosswalks or the programming processes within the DWH.

Risk Adjustment

To determine appropriate risk-adjustment procedures two subprojects were carried out. First, the UYORK team reviewed (using systematic methods of searching and critical appraisal) the extensive literature comparing risk-adjustment methods and in particular co-morbidity indices. Second, an empirical comparison of the performance of the two leading comorbidity indices (the Charlson/Deyo and Elixhauser comorbidity indices) was carried out using ECHO data from five countries in 2008-2009. Three inpatient groups commonly used in hospital quality comparisons were included: mortality rates following coronary artery bypass graft surgery, acute myocardial infarction and stroke. The two indices were compared with each other and with a simple model including only patient age and sex, in terms of model discrimination, calibration and goodness of fit, with internal and external validation. The Elixhauser Index was found to have better overall predictive ability in terms of discrimination and goodness of fit than the Charlson/Deyo index or an age-sex only model. All models are well calibrated in all conditions. These findings are robust to the choice of country, to pooling all five countries and to internal and external validation. For the purpose of ECHO we judged the Elixhauser index to be a preferable measure.

DRG weighting

DRG weighting is a particular case of risk adjustment specifically used in comparison of technical efficiency. Only discharges from Portugal and Spain were grouped using DRG grouping system (just these two countries coded using ICD9th in both diagnoses and procedures). Given this limitation, technical efficiency analyses have followed an alternative approach allowing the other countries to be included; so, hospital discharges have been adjusted by multiplying each discharge by its relative weight³ according to the patient classification system in use in each country.

Mapping out intermediate layers

Geographic variation studies aim at eliciting systematic variation, therefore, variation not attributable to chance. A phenomenon that might jeopardize this goal is the extra-variation related to population size heterogeneity across the geographic areas. Getting sounder estimates of variation requires paying attention to the unit of analysis and the variation estimators. The critical issue with units of analysis is their frequently heterogeneous size - the more the heterogeneity the more likely observing extra-variation amenable to population's size rather than to practice variation. These issues are even more important in international comparisons when putting side by side units with enormous heterogeneity, both in size and event prevalence, within and across countries.

The ECHO approach was to build an intermediate layer to reduce heterogeneity preserving the meaningfulness of the units of analysis for decision-making purposes. The construction of these new units of analysis had to attain two goals: 1) reflecting the actual population exposure to hospital care, and 2) being respectful with the limits of the existing upper administrative level.

³ In England, instead of relative weights, a tariff expressed in pounds is associated to each HRG. To make similar adjustments to hospital discharges, tariffs were converted to relative weights.

Beyond some effect on the local interpretation of variation and rates in the new geographical units as compared to that one in the older areas, building greater units of analysis entails a change in the estimates of variation. It naturally implies less extreme values and lower exposure to random phenomena, and as a consequence more reliable estimates.

Benchmarking in ECHO

An essential element in the ECHO performance measurement framework is the construction of benchmarks.

Given the advantage of the availability of individual-patient data in a single database, and the allocation of each hospital admission into a geographic area (place of residence) or into a hospital of treatment, ECHO is able to construct robust in-country and cross-country benchmarks.

In the case of the geographic analyses, the benchmark is determined by estimating the expected number of cases in a geographic area, either using a population of reference (direct standardization) or the age-sex specific rates in the standard population (indirect standardization). When the interest is in the national benchmark the standard of reference is the national “population”, while the ECHO population is used when the interest is in the international comparison.

In the case of hospital-specific analyses, the expected number of cases is estimated using logit-type multilevel analyses. When the interest is in-country benchmarking the models use all the patients and hospitals in a specific country; in turn, international benchmarks are estimated using the whole sample of patients and hospitals in ECHO.

ECHO Atlases usually report performance indicators with both national and international benchmarks. But, ECHO allows benchmarking between pairs of countries, as well. This allows country A be compared with the best country within the ECHO sample, providing a sort of aspirational reference for each indicator.

Methodology standardisation

The ECHO Handbook on Methods is meant to critically describe those methodological approaches and analytical techniques used in ECHO (see table), throughout either brief reviews or case studies. Thought as an on-line publication, the Handbook contains those methods upon which the “ECHO Atlas reports” have been constructed. The handbook will be progressively nurtured with new entries detailing those methods used to answer those research questions stemming from the interaction between the ECHO consortium and the ECHO research infrastructure.

ECHO methodological approaches

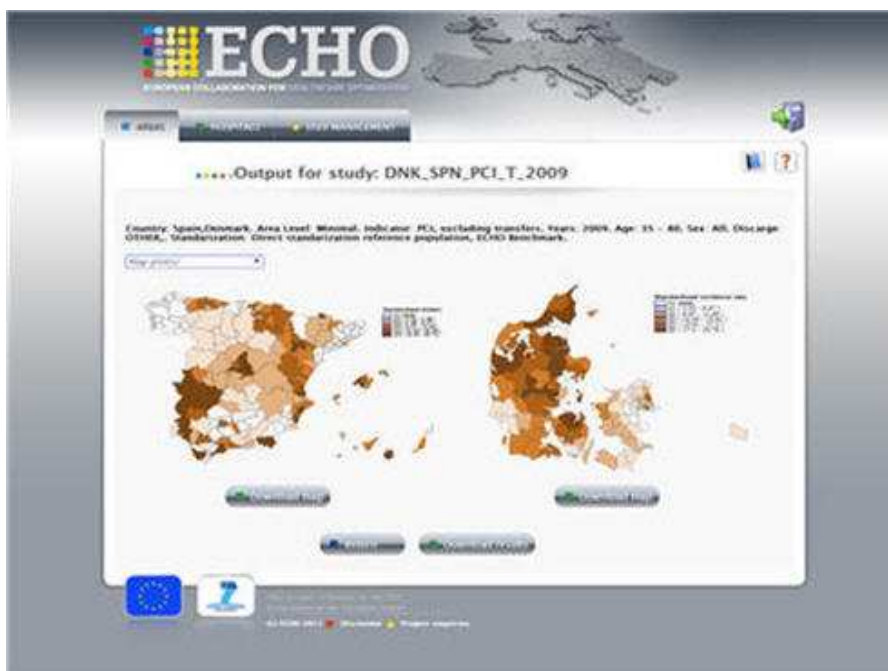
| | Geographic approach | Hospital-specific approach |
|-------------------|---|--|
| Research question | Does the place of residence influence the population experience of getting effective and safe care? | Is the exposure to high-quality and safe care dependant on the provider where a patient is assisted? |
| Main endpoint | Standardised rate or Standardised Utilization Ratio for hospital admissions or procedures | Adjusted risk and Observed to Expected Ratio, analysing events amenable to healthcare quality |
| Denominator | Population living in a pre-defined geographical area | Patients treated in a hospital |
| Main audience | Policy - makers | Managers Clinicians |

Final Report

Rather than a single report, the ECHO consortium decided in the previous reporting period to produce several Atlas reports, with both international and in-country sections. While the first one is merely a snapshot of the situation of a particular country with regard to the other using the most recent information, the second one includes also in-country trends for each performance indicator, differences across socioeconomic quintiles and policy implications. ECHO delivers three Atlases reports on unwarranted variations in performance: atlas on coronary revascularization, atlas on lower value procedures and atlas on potentially avoidable admissions in chronic conditions.

ECHO Tool

Going beyond the regular dissemination channels, the web-tool allows a straightforward use of sophisticated statistical apparatus; logged stakeholders can replicate or create their own analysis without needing a good command of the underlying statistical techniques.



Summing up, the above streams of work have produced a set of original research results:

- A refined set of accurate performance measures.
- Reliable information about the actual performance of different providers and different health systems.
- Methodological insight to overcome some of the classical barriers for adequate performance measurement.
- A set of web-based analytical tools to replicate methods and analyses on more specific and local problems.

Impact, Dissemination, Exploitation & Collaboration Impact

IMPACT

ON FUTURE RESEARCH

ECHO was conceived as a demonstration project aimed at testing whether creating a research infrastructure based on routinely collected data from different countries was feasible, whether making those data comparable was reliable, and whether analysing performance across healthcare systems was accurate. ECHO has fairly succeeded in those tasks creating a starting community that could allow further development on the field of health care performance and policy analysis.

Actually, several institutions across Europe have explicitly expressed interest in joining this community and eventually contributing their national datasets to the ECHO knowledge infrastructure. The referred institutions are: INAMI-Ministry of Health in Belgium, STAMPAR-Institute of Public Health in Croatia, IRDES-Institute for research and information in Health Economics in France, SSSUP-Scuola Superiore Sant'Anna di Pisa in Italy, NIVEL-Netherlands Institute for Health Services Research in The Netherlands, University of Debrecen in Hungary and UNIBERN-University of Bern, in Switzerland.

Last but not least, ECHO has been invited to provide its expertise the meetings of the European Commission EGHI Ad hoc Core Working Group on the potential ERIC on health information. This Experts Group on Health Information is exploring avenues for a long-term health information and knowledge system that would provide harmonized and comparable indicators at national and at EU level with the objective of following trends, serving as a foundation for evidence-based policy and being a basis for research projects.

ON POLICY-MAKING

Local Dissemination Groups at ECHO have actually been an experimental ground where analysing the potential impact of ECHO methods and findings. The interaction with 160 different stakeholders (policy-makers, managers, public health officers, data-analysts, patient-representatives, professional organizations, etc.) provided three main messages: a) a project like ECHO is relevant for decision-making at local level; b) the way results are made public is important to foster change, being the Atlas reports and the ECHO tool appropriate mechanisms; and, c) stakeholders need up-to-date information to support their decisions, encouraging ECHO to continue the endeavour.

While LDGs provided insight at national level, ECHO concept and methods have been deemed meaningful by different international institutions –EC, OECD and WHO Observatory of Health Systems and Policies. As a matter of fact, ECHO was invited to debate the potential implications of the project at DG SANCO (Unit on Healthcare systems -October 2012) and presented at DG SANCO Working Group on Patient Safety and Quality in February 2014. ECHO is providing expert advice to the OECD project on Medical Practice Variations and will participate in the biannual meeting of the Healthcare Quality

indicators Project (Q2 2014). Finally, ECHO has been invited to attend the Expert Meeting to review the Joint Assessment Framework on Health (JAF Health) meant to screening device to detect possible challenges in Member State's health systems, with a specific focus on access, quality and equity (DG Employment Q2 2014).

Dissemination

Local Dissemination Groups

ECHO presented a two-fold challenge in promoting the project's findings: Firstly, the data does not speak for itself but requires further questioning and investigation – the project does not provide piece-meal analyses but conversation starters which need to be assessed in the right way by different target groups. Secondly, different target groups (including policy makers, health managers, and medical specialists) have specific perceptions and preferences on how to use data for decision-making. This requires a 'dialogue model' to engage with the different target groups and to moderate their dialogue.

In order to support these conversations the European Health Management Association in cooperation with all partners in the ECHO project developed a series of so-called "Local Dissemination Groups". The approach to the Local Dissemination Groups (LDGs) was to have two meetings in each of the involved countries. Local project partners played an essential role in identifying the right participants for their respective system, and used their networks and clout to get those stakeholders to the meeting. IACS played a key role in preparing material and presenting the projects output.

The aim of the first round of meetings was (1) to validate output of the ECHO project, (2) to learn about how target groups rate the presentation of the project's output, and (3) to promote the project. Participants were asked to fill in a questionnaire on the correctness and usefulness of the presented data, which both were measured using a Likert-scale; there was also space for additional comments.

The aim of the second round of meetings was (1) to discuss uptake and use of project output by different stakeholders and promoting their cooperation, and (2) to learn about barriers and opportunities, and stakeholders' willingness to use the output of the ECHO project. During a discussion session under the Chatham House Rule with different stakeholders their views and input were noted.

A number of general learning points from the first round of LDGs illustrate the interaction between target groups and the project consortium, and how the feedback from the target groups was taken into account when presenting the ECHO output. For instance, the use of colours on the map and in the funnel plots was improved as didn't help people who are colour blind, and overall participants of the LDGs considered the colour scheme confusing (red and green dots; too similar colours e.g. red and pink).

Feedback often reflected challenges within the countries' health systems. Main topics included the role and trust in quality of data, which indeed was different in each country. Provided causes for variations showed similarities across the countries; lack of use of evidence and guidelines, lack of a leading

organisation or institution to drive the agenda and reduce variations in health services delivery, and – on the demand side – supplier induced demand resulting in overexposure.

In total, the LDGs reached over 160 in-country stakeholders. Ideally, this number would have been larger (also here some countries showed a higher interest than others), and it could have included more policy makers.



Attendees at the Spanish LDG

Conferences

Preliminary results have been shown in multiple international scientific conferences such as Health Services Research Europe, iHEA World Congress, Dartmouth Institute for Health Policy and Clinical Practice, Wennberg International Collaborative, European Health Forum, EHMA Annual Conference or EUPHA, where the ECHO final conference took place.

Final Conference

The ECHO project's final conference took place on 13 November 2013 in Brussels at the SQUARE venue, organised as a EUPHA pre-conference symposium by the European Health Management Association.

During the final conference results have been presented, showing how the involved countries can improve the access, safety and utilisation of their healthcare services. The emphasis was on how

unwarranted variation can be tackled, and which areas of care are in need of improvements. In short, the aims of the conference were: To promote the findings of the project around safety, quality, access and efficiency of healthcare delivery; and To discuss how the impact on managerial and policy decisions can be optimised. 50 delegates participated in this free final conference.



Project partners presented the work carried out, and the day concluded with an interesting policy discussion including the European Commission DG SANCO, the OECD, and the European Observatory on how ECHO could inform Health Systems and Policies across Europe.

Supplement

Noticeably, ECHO has contracted with Oxford University Press the publication of a supplement in the European Journal of Public Health, including a number of papers reflecting the work done by ECHO. Several papers are being drafted with the following working titles:

1. Editorial
2. ECHO Overview: methodological challenges in international performance measurement
3. Comparing the performance of the Charlson/Deyo and Elixhauser co-morbidity indices across five European countries and three conditions
4. Making areas comparable for international comparisons: the case of Denmark, Portugal and England
5. Comparing hospital performance within and across countries: an illustrative study of coronary artery bypass graft surgery in England and Spain
6. Trends in socioeconomic inequality in effective procedures - methodological case study of six European countries from 2002-9
7. Poor quality of ambulatory care: case study of the overall rate of potentially avoidable hospitalizations in six chronic conditions
8. Variations in lower-value procedures – case study of C-section in low risk deliveries
9. Variations in hospital efficiency - an approach using SFA
10. Translating ECHO findings into practice: results and learning from LDGs

Exploitation

The ECHO Tool Software, the ECHO DWH and its compound, the ECHO Tool constitute relevant foreground of the ECHO Project.

The ECHO DWH is a database of all partners' raw data concerning each party's national healthcare system. Using this ECHO tool software, online logged users accessing through the ECHO webpage <http://www.echo-health.eu/> will perform comparisons between and within English, Danish, Portuguese, Slovenian and Spanish regions, countries and hospitals.

Exploitation of the ECHO DWH

The consortium extensively discussed the possibilities, advantages and disadvantages of charging for the delivery of aggregated data.

Possible positive effects of delivering aggregated data to other parties include:

1. Could create some finance to continue ECHO work as well as covering costs
2. Could ensure that ECHO data is used to improve healthcare in countries
3. Could raise the profile of ECHO so potentially attracting more funding/avenues of funding

However, the discussion reflected a range of technical/practical and ethical issues:

1. Requires cooperation of all partner countries for European comparison (all partners need to agree to collect and analyse data on a yearly basis).
2. The ethical clearance for countries may not allow for 'sale' of data; at the moment of writing a heated discussion takes place in England⁴ about the availability of pseudonymised data to private companies including the pharmaceutical industry
3. The rules on destruction of data by a certain date for some countries means that longitudinal data may not be available decreasing the attractiveness of what could be on offer
4. It is not clear that the costs of collecting/analysing data could be covered by sale (including necessary back-room staff)

The shared view of the consortium was that the offer would be very limited, in particular taking note of the technical and ethical clearances involved.

⁴ "Better information means better care", page available at <http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/care-data.aspx>. Last accessed on 12/02/2014

Exploitation of the ECHO tool software

There is an opportunity to explore commercial exploitation of the methodology and technical infrastructure behind the ECHO Tool.

The ECHO Software is an innovative initiative in healthcare performance because:

- a) It enables the analysis of variation at provider level rather than the analysis of average measures.
- b) It pools individual patient data from different sources using different codification languages.
- c) It enables to analyse performance at levels of disaggregation meaningful from the perspective of the stakeholders –country, region, healthcare area and hospital.
- d) It also allows the linkage with other sources containing relevant information from the point of view of stakeholders –socioeconomic status of the areas where the patients live, for example.
- e) It is flexible enough to implement both the simplest graphs and the most sophisticated analyses and plots by linking the dataset feeding the tool.

To sum up, the added value of the Tool is on the implementation of ground breaking scientific methodology and IT solutions into the decision-making arena. ECHO software mining technology is capable of pooling thousand of registries from different countries, using different codification languages, making them comparable over time. At the same time, the Tool implements sophisticated mathematical analyses that support the robustness and reliability of the outputs.

Contact details

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- Institute of Public Health of the Republic of Slovenia (NIJZ), Slovenia
- University of York - Department of Health Sciences (UYORK), England
- Private University for Health Sciences, Medical Informatics & Technology (UMIT), Austria
- University of Southern Denmark - Institute of Public Health (SAM_SDU), Denmark
- European Health Management Association Ltd (EHMA), Ireland

Collaborator

- Atlas VPM

4.2 Use and dissemination of foreground

1. Introduction

1.1 Introduction to the plan

This plan on the dissemination of foreground outlines the use and dissemination of the project results after the project is terminated. In addition to a brief review of the dissemination activities carried out during the lifetime of the project, this plan describes the consortium detailed plan for the management of foreground (*process of dissemination*) and includes some of the directions or activities the consortium could take to increase the sustainability of the project's results (*content of post-project dissemination*). As such it is an update of the dissemination plan and the initial plan for dissemination and exploitation of project results, which has been included in the Description of Work.

Foreground has been defined by the European Commission as “the results, including information, materials and knowledge, generated in a given project, whether or not they can be protected. It includes intellectual property rights (IPRs) such as rights resulting from copyright protection, related rights, design rights, patent rights, plant variety rights, rights of creators of topographies of semiconductor products), similar forms of protections (e.g. sui generis right for databases and unprotected know-how (e.g. confidential material). Thus, foreground includes the tangible (e.g. prototypes, micro-organisms, source code and processed earth observation images) and intangible (IP) results of a project.” A summary of the Foreground rules of the ECHO Consortium Agreement is included in Section 1.2 of this Plan. This document discusses the use of all products and materials delivered by the project, and how project partners can use this foreground after the project has been finalised.

In addition, activities to increase the sustainability of the initiative are discussed. In order to guarantee the continuity of the project after its initial funding through the Seventh Framework Programme, the consortium agreed on the following activities:

- analysis of activities carried out and obtained results;
- analysis of the possibilities of setting up new projects based on the results of ECHO;
- analysis of funding opportunities;
- study of possible partners interested in joining the consortium;
- coordination of activities/plans of consortium partners and possible key stakeholders in the field, analysing activities led by each WP leader and related results;
- mapping exercise to evaluate current state of affairs and dissemination activities during the course of the project: What has been achieved? Which tools/strategy were particularly successful? Where is further need for dissemination and/or research? What are risks and factors to be taken into account?

1.2 Consortium agreement concerning the general use of foreground

The consortium agreement “remains in full force and effect until complete discharge of all obligations for carrying out of the Project ... [and] shall be revised – and possibly terminated – a maximum of 5 years after the date of completion of the project” (consortium agreement article 9.4, p.22). This section summarises the agreement made between project partners concerning the use of foreground as laid down in the project’s consortium agreement.

1. Background

Ownership of background is not affected by the Consortium Agreement and therefore each project partner remains owner of its background. Other partners may have access to this background information if they need to make use of this data to carry out their tasks, *and* if the owner of the background is allowed to provide this information. This is important when considering, for instance, national patient records.

2. Foreground

Ownership of foreground is with the party that carried out the work that generated that specific foreground.

3. Joint Ownership

Where multiple parties have jointly carried out work generating common foreground and where their respective share of the work cannot be determined, project partners shall have joint ownership of such foreground. The parties need to agree among themselves about the allocation and terms of exercising ownership, however this share will depend on the intellectual contribution each party made to the developed foreground. In practical terms, this is outlined in section 3.

To support and supplement the rules outlined in the consortium agreement with a number of practical rules:

1. In case of joint ownership, the partner that wants to use the foreground will contact the other joint owners as far in advance as possible. If the foreground is owned by the whole consortium, communications might go via the IACS.
2. Project partners are also encouraged to inform the project coordinator of their post-project activities using the project’s foreground.

1.3 Guide for publications

Project partners agreed on adhering to a brief guide outlining good practices for publication. This briefing will remain valid for the period after the project has ended.

To do (prior to start drafting):

1. Inform the dissemination partner (EHMA at Paul.Giepmans@ehma.org) and coordinator (IACS at rlaunag.iacs@aragon.es) about your plans regarding scientific publications to allow for coordination;

2. Confirm with colleagues the activities you are about to undertake, defining them in an abstract. The details of any proposed article⁵ intended for publication in connection with, or relating to, the ECHO Project shall be sent to EHMA and IACS at the earliest time possible.

To include (while drafting):

1. FP7 disclaimer: *The research leading to these results has received funding from the European Community's Seventh Framework Programme (FP7/2010-2013) under grant agreement n°242189. Sole responsibility lies with the authors and the European Commission is not responsible for any use that may be made of the information contained therein.*

Reference to authors⁶ and the project consortium (for instance “on behalf of the ECHO Consortium”) according to the format requested by the specific publication. Project partners have a list of participating researchers in the project.

To negotiate with the Publisher:

A number of obligations are included in the European Commission Grant Agreement regarding dissemination that could eventually conflict with the publishing agreement.

To ensure compliance with EC rules, we ask project partners to request and share the publishing agreement⁷ with EHMA as soon as possible while copying in IACS. We will check it against the Grant Agreement and will, in cooperation with the leading author, determine the next steps to take to pursue issues such as open access.

Annex I European Commission Dissemination Policy

The European Commission seeks to have the project’s entire foreground as accessible as possible. The Commission’s dissemination guide spends quite some attention to scientific publications and related IPR issues – for a full overview please check section [7.3. Relations with publishers of scientific journals, p.16 onwards](#).

Open access obligation: ‘Open Access’ is concerned with making digital content available free of charge without restriction. This in order to bring publicly funded research into the public domain as soon as possible.

⁵ [Guide for dissemination](#), p.14: “Each participant shall ensure that the foreground it owns is disseminated as swiftly as possible. However, any dissemination (including publications or on web-pages) should be delayed until a decision about its possible protection has been made (through IPR or trade secrets). The other participants may object to the dissemination activity if their legitimate interests in relation to their foreground or background could suffer disproportionately great harm.”

⁶ Authorship credit should be based on 1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; 2) drafting the article or revising it critically for important intellectual content; 3) final approval of the version to be published. Authors should meet conditions 1, 2, and 3

⁷ The Publishing agreement is signed between the author and the publishers by which the author grants certain rights to the publisher

Special clause 39⁸ included in the ECHO project's GA foresees a period of 6 months prior to open access. This 6 months "embargo" allows scientific publishers to ensure a profit on their investment (by charging for journal subscription), while then providing open access to research articles once the embargo period has lapsed.

However, in some cases, the specific policy of the journal envisages longer embargo periods⁹. That's why EHMA and IACS need to receive a copy of any such publication agreement prior to signature.

The publishing agreement will be reviewed and, if needed, an exception to the publisher's policy will be requested in order to comply with the EC policy. If that is not possible, EHMA and IACS will inform the EC at rtd-open-access@ec.europa.eu and the EC project officer on the failure of "best efforts" to comply and will ask the leading author to achieve free electronic availability as soon as possible and directly after the embargo period ends.

Obligation to provide the material to the EC for publication: a contractual provision could be inserted in the publication agreement, for example: "The publisher agrees that the author retains the right to provide the European Commission for publication purposes with an electronic copy of the published version or the final manuscript accepted for publication."

⁸ Special clause 39 reads as follows: Beneficiaries shall deposit an electronic copy of the published version or the final manuscript accepted for publication of a scientific publication relating to foreground published before or after the final report in an institutional or subject-based repository at the moment of publication.

Beneficiaries are required to make their best efforts to ensure that this electronic copy becomes freely and electronically available to anyone through this repository:

- immediately if the scientific publication is published "open access", i.e. if an electronic version is also available free of charge via the publisher, or
- within 6 months of publication.

⁹ For instance, in the case of the European Journal for Public Health (Oxford University Press) authors may upload their accepted manuscript PDF ("a post-print") to institutional and/or centrally organized repositories, but must stipulate that public availability be delayed until 12 months after first online publication in the journal.

2. Section A: Dissemination measures

2.1 Introduction to the overview of dissemination measures

The delivery of the ECHO project and its deliverables has had a significant impact on the dissemination activities of the project. The foreseen aim and structure of activities (as presented in the initial dissemination plan) were originally split in three years, with the first year promoting the project as such, the second year engaging stakeholders through Local Dissemination Groups, and promotion of findings and results in the third year. In practice however delays in the delivery of the project – and in particular the required input for the Local Dissemination Groups - resulted in changes in this broad schedule. All partners agreed in October 2011 to reduce (or not increase) the dissemination activities in order not to gain momentum too early – as actual results were not available and project partners considered it not beneficial to deliver the same story over and over. However, all project partners kept actively promoting the project, with the coordinator especially doing a stellar job in building strategic connections with the Organisation for Economic Co-operation and Development (OECD) and the European Commission.

2.2 Promoting the project and its aims in Europe and beyond

All project partners promoted and presented the ECHO project to a large group of target groups across the European region. In addition, the coordinator, IACS, has been discussing the development of the project with colleagues from the United States with long-time experience in mapping variations in healthcare delivery.

The project has been presented in the countries it covers i.e. Spain, England, Portugal, Denmark, Austria and Slovenia. In addition it was promoted through presentations and active participation in conferences in Sweden, Switzerland, Italy, the Netherlands and Luxembourg, thus reaching large groups of (mostly) policy makers. Presentations in Australia and the United States of America do not only underline the importance of the project in Europe but also indicate the international interest in the project and the challenges that ECHO addresses.

Through presentations and dedicated ECHO sessions at the European Health Management Association's Annual Conference, a mixed audience of policy makers, health managers and academics were reached, whereas the EUPHA conference gave access to mostly an academic audience.

ECHO coordinator IACS delivered several presentations at the OECD Expert Meeting On Medical Practice Variations and presentations with the European Commission DG SANCO and its working group on patient safety and quality. This did not only allow the project to reach stakeholders on European level, but also showed the support of the European community in presenting the project to Member State policy makers.

2.3 Delivering peer reviewed publications

From early 2013 onwards the consortium started to focus actively on the delivery of peer reviewed publications. Earlier the following articles were prepared:

- *York: Comparing the performance of the Charlson/Deyo and Elixhauser comorbidity indices in low-morbidity English and Spanish inpatient populations – BMC HSR under review*
- *York+IACS: Comparing hospital performances across countries: opportunities and challenges – targeted journal BMJ in preparation*
- *ENSP: Comparing efficiency in Portuguese and Slovenian hospitals using SFA*
- *SDU: “How to make comparable health care areas in five European countries when studying the regional variation in the use of PTCA” – in preparation*

In addition, the European Health Management Association scoped and explored different opportunities to publish articles collectively produced by the ECHO consortium in a peer-reviewed journal supplement. This way all scientifically valuable materials could be collected and be made available to the scientific community. This decision also implied a decision not to publish a book – a journal supplement was considered more appropriate given the volume of the material and the time and costs it would involve to produce a book. The European Journal of Public Health, the International Journal for Quality in Healthcare; Health services research; BMJ quality and safety; Health Economics, Policy and Law; Health Policy; and Health and Place have all been considered. A decision was made based on audience, impact factors and price, resulting in the selection of the European Journal for Public Health as the targeted journal, and contracts have been agreed early 2014.

The index for the journal supplement is as follows.

| (working) title | First author(s) | Contributing authors | Outline |
|--|--------------------------------------|---|--|
| Overview of the European Collaborative for Healthcare Optimization: methodological challenges in international performance measurement | Enrique Bernal-Delgado | The whole consortium | Overview detailing: the aims and scope of ECHO, the performance model, a rough detail of the knowledge infrastructure and the metrics – value and variation. |
| Access to effective care in ECHO countries: case study on coronary revascularization | Enrique Bernal-Delgado | | |
| Trends in socioeconomic inequality in effective procedures - methodological case study of six European countries from 2002-9 | Richard Cookson, Terkel Christiansen | Sandra Garcia Armesto, Ester Angulo, Nils Gutacker, Karen Bloor; Enrique Bernal-Delgado | Countries: Denmark, England, Portugal, Slovenia, Spain ... plus Austria if available in time Procedures: hip replacement, knee replacement, emergency admissions for CHF, emergency admissions for angina |

| | | | |
|---|---|--|--|
| Poor quality of hospital care: mortality after coronary revascularization | Karen Bloor | Nils Gutacker, Richard Cookson, Sandra García-Armesto and Enrique Bernal-Delgado | |
| Poor quality of ambulatory care: case study of the overall rate of potentially avoidable hospitalizations in six chronic conditions | Terkel Christiansen, Lau Thygesen, Enrique Bernal-Delgado | | |
| Mortality and length of stay after acute myocardial infarction: an approach to the efficient use of hospital resources | Nils Gutacker | Karen Bloor, Richard Cookson, Sandra García-Armesto and Enrique Bernal-Delgado | |
| Variations in lower-value procedures – case study of c-section in low risk deliveries | Sandra García-Armesto | Céu Mateus; Inês Joaquim | |
| Variations in hospital efficiency - an approach using SFA | Ceu Mateus | Carla Nunes; Inês Joaquim | |
| Translating ECHO findings into practice: results and learning from LDGs | Jeni Bremner | Anne-Marie Yazbeck, Olivia Dix, Paul Giepmans | <p>Article explaining the LDG and Policy Dialogues, as well as some lessons learnt from their development. What should be expected from ECHO?</p> <p>Outline:</p> <ul style="list-style-type: none"> ➤ Introduction and aim of the Local Dissemination Groups (knowledge transfer) ➤ Methodology ➤ Implementation of the groups ➤ Overall findings from the groups ➤ Conclusions and next steps |

2.4 Interactive dissemination through Local Dissemination Groups

The 'Local Dissemination Groups' (LDGs) serve to link scientific results with day-to-day decision making in the health institutions and raise the awareness of the project's findings and recommendations externally. Using this methodology provides the ECHO project with a mechanism to test and validate products and findings of the ECHO project by an external body of experts, policy makers, managers and health professionals as well as to promote those products and findings among potential users and audiences.

EHMA implemented the groups in each of the six countries using a structured format. The project partners played a crucial role in identifying the right participants. The results and output are shaped as reports and made available on the ECHO website. Some of the outcomes have been communicated to the consortium members with the aim to improve other deliverables.

2.5 Overview of publications and activities

Scientific Papers have not been published yet.

| TABLE A2: LIST OF DISSEMINATION ACTIVITIES | | | | | | | | |
|--|----------------------------------|-------------|-------|-----------------------|----------------------------|--------------------------------|------------------|---------------------|
| NO. | Type of activities ¹⁰ | Main leader | Title | Date | Place | Type of audience ¹¹ | Size of audience | Countries addressed |
| | Atlas VPM event | IACS | | 20-21 May 2010 | Vitoria, Spain | SC | <50 | National level |
| | EHMA 2010 Conference | EHMA | | 30 June – 2 July 2010 | Lahti, Finland | PM, HM, I, CV | 200 | International level |
| | The Wennberg Conference | IACS | | 14–15 September 2010 | London, UK | SC, CS, PM, I, M | >50 <200 | International level |
| | EUPHA conference | IACS | | 10-13 October 2010 | Amsterdam, the Netherlands | SC, CS, PM, I, M | >500 | International level |
| | Casemix | ENSP | | 13-17 June | Evora, | SC | | International level |

¹⁰ A drop down list allows choosing the dissemination activity: publications, conferences, workshops, web, press releases, flyers, articles published in the popular press, videos, media briefings, presentations, exhibitions, thesis, interviews, films, TV clips, posters, Other.

¹¹ A drop down list allows choosing the type of public: Scientific Community (higher education, Research), Industry, Civil Society, Policy makers, Medias ('multiple choices' is possible).

| | | | | | | | | |
|--|---|------|---|---------------------|---------------------|------------------|-------|---------------------|
| | Summer School | | | 2011 | Portugal | | | |
| | EHMA Annual Conference 2011 | EHMA | | 22-24 June 2011 | Porto, Portugal | PM, HM, I, CV | > 200 | International level |
| | EUPHA conference | York | | 10-13 November 2011 | Copenhagen, Denmark | SC, CS, PM, I, M | >500 | International level |
| | OECD Expert Meeting On Medical Practice Variations | IACS | Atlas of variations in medical practice in Spain. | 2 April 2012 | Paris, France | SC, CS, PM, I, M | | International level |
| | OECD Expert Meeting On Medical Practice Variations | IACS | European Collaboration on Healthcare Optimization (ECHO). | 2 April 2012 | Paris, France | SC, CS, PM, I, M | | International level |
| | ISS meeting | York | | 18-20 June 2012 | Stockholm, Sweden | | | |
| | ECHE meeting | IVZ | | 19-20 July 2012 | Zurich, Switzerland | SC | | International level |
| | Observatory Summer School, | IVZ | | 22-27 July 2012 | Venice, Italy | PM | | International level |

| | | | | | | | | |
|--|---|------|---|----------------------|---------------------------|------------------|----------|---------------------|
| | WHO | | | | | | | |
| | IQ Healthcare seminar: more quality – less variation | EHMA | | 6-7 September 2012 | Nijmegen, the Netherlands | PM, SC | 200 | National level |
| | The Wennberg Conference - London School of Economics | IACS | ECHO: a healthcare performance research initiative in progress. | 10-12 September 2012 | London, UK | SC, CS, PM, I, M | >50 <200 | International level |
| | The Wennberg Conference - London School of Economics | IACS | Disinvestment in the age of cost-cutting sound and fury. Tools for the SNS. | 10-12 September 2012 | London, UK | SC, CS, PM, I, M | >50 <200 | International level |
| | 4th Workshop APES on Policy and Health Economics | ENSP | ECHO: on DRG costs and efficiency. | 14-16 September 2012 | Evora, Portugal | | | National Level |
| | EHPG meeting | York | | 20-21 September 2012 | London, UK | SC, PM | | International level |

| | | | | | | | | |
|--|---|------|--|------------------|------------------------|--------|-----|---------------------|
| | European Commission DG SANCO | IACS | ECHO: European Collaboration for Healthcare Optimization An international project on healthcare performance. | October 2012 | Brussels, Belgium | PM | | International level |
| | HONCAB Kick-off meeting | IVZ | | 24 October 2012 | Luxembourg, Luxembourg | PM, SC | | International level |
| | 4th Workshop on Efficiency and Productivity Analysis | ENSP | ECHO on DRG costs and efficiency. | 29 October 2012 | Porto, Portugal | SC | | National level |
| | OECD 2013 | IACS | | 25-26 April 2013 | Paris, France | | <50 | |
| | AES 2013 | YORK | | 19 June 2013 | Santander, Spain | | <50 | |
| | EHMA Annual Conference | EHMA | Moving Towards Safer and More efficient health services - evidence from the ECHO | 28 June 2013 | Milan, Italy | PM, SC | <10 | International level |

| | | | Project. | | | | | |
|--|--------------------------------|-----------------------|--|-------------|-------------------|----|--|---------------------|
| | 9th World Congress iHEA | IACS, SDU, York, ENSP | <p>Analysing unexplained variations in performance to increase the efficiency of health care: Case studies from the ECHO Project.</p> <p>Measuring hospital efficiency using stochastic frontier analysis: A comparative analysis of hospitals in Europe.</p> <p>What explains variation in length of stay and mortality across Europe?</p> <p>How to make comparable health care areas across European countries.</p> | 9 July 2013 | Sydney, Australia | SC | | International level |

| | | | | | | | | |
|--|--|------------|--|-------------------|---------------------|--------|------|---------------------|
| | | | Using geographical analysis to enhance allocative efficiency: opportunity cost and low value care. | | | | | |
| | Local Dissemination Group round 1: Portugal | EHMA, ENSP | | 3 September 2013 | Lisbon, Portugal | SC, PM | 25 | National level |
| | Local Dissemination Group round 1: Slovenia | EHMA, IVZ | | 9 September 2013 | Ljubljana, Slovenia | SC, PM | 25 | National level |
| | Local Dissemination Group round 1: England | EHMA, York | | 17 September 2013 | York, UK | SC, PM | 10 | National level |
| | Local Dissemination Group round 1: Denmark | EHMA, USD | | 24 September 2013 | Copenhagen, Denmark | SC, PM | 20 | National level |
| | Dartmouth Institute for | IACS, | ECHO: European Collaboration | October 2013 | Hanover, | PM, SC | + 50 | International level |

| | | | | | | | | |
|--|---|------------|---|------------------|---------------------|--------|------|---------------------|
| | Health Policy and Clinical Practice | YORK, ENSP | for Healthcare Optimization An international project on healthcare performance. | | NH, UK | | | |
| | European Health Forum Gastein | EHMA | Moving towards safer and more efficient health services – evidence from the ECHO project on systematic variations in healthcare delivery. | 3 October 2013 | Gastein, Austria | PM, SC | <20 | International level |
| | ECHO Final Conference | EHMA | | 13 November 2013 | Brussels, Belgium | PM, SC | <100 | International level |
| | Local Dissemination Group round 2: Denmark | EHMA, USD | | 21 January 2014 | Copenhagen, Denmark | SC, PM | 10 | National level |
| | Local Dissemination Group round 2: | EHMA, IVZ | | 4 February 2014 | Ljubljana, Slovenia | SC, PM | 20 | National level |

| | | | | | | | | |
|--|---|------------|--|------------------|-------------------|--------|-----|----------------------------------|
| | Slovenia | | | | | | | |
| | Local Dissemination Group round 2: Portugal | EHMA, ENSP | | 6 February 2014 | Lisbon, Portugal | SC, PM | 15 | National level |
| | Local Dissemination Group round 2: England | EHMA, York | | 13 February 2014 | London, England | SC, PM | 10 | National level |
| | European Commission Working Group for Patient Safety and Quality | IACS | | 14 February 2014 | Brussels, Belgium | PM | <50 | International and national level |
| | European Commission Working Group for Patient Safety and Quality | EHMA, IACS | | 14 February 2014 | Brussels, Belgium | PM | <50 | International level |
| | Local Dissemination Group round 2: Spain | IACS | | 20 February 2014 | Madrid, Spain | SC, PM | | National level |

3. Section B (CONFIDENTIAL): Exploitable foreground and plans for exploitation

This section covers agreements concerning the use of foreground. According to Grant Agreement Annex II. II. 29 the beneficiaries shall report on the expected use to be made of foreground in the plan for the use and dissemination of foreground.

More specifically, this covers the Intellectual Property Rights (IPR) the expected use to be made of the ECHO tool, the ECHO tool software ownership and license agreement, and the ECHO website and related platforms as they will be used to further promote the project’s output.

3.1 Overview of exploitable foreground

| Type of Exploitable Foreground ¹² | Description of exploitable foreground | Confidential Click on YES/NO | Exploitable product(s) or measure(s) | Sector(s) of application ¹³ | Timetable, commercial or any other use | Patents or other IPR exploitation (licences) | Owner & Other Beneficiary(s) involved |
|---|---|------------------------------|--------------------------------------|--|--|--|---|
| ECHO Tool (European Infrastructure on Health Information) | A database data from 5 EU countries : hospital discharges produced in the last 9 years (around 200 million records) | YES | See Section 3.2 | Public Health Research, Policy making | 2014 | N/A | Datasets not own by ECHO partners. ECHO tool open to all interested parties (though gradual launching); |

¹⁹ A drop down list allows choosing the type of foreground: General advancement of knowledge, Commercial exploitation of R&D results, Exploitation of R&D results via standards, exploitation of results through EU policies, exploitation of results through (social) innovation.

A drop down list allows choosing the type sector (NACE nomenclature) : http://ec.europa.eu/competition/mergers/cases/index/nace_all.html

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| | | | | | | | |
|--------------------|---|-----|-----------------|--------------------------------------|----------------------|---|---|
| ECHO tool Software | software to process and summarise data in real time and to generate outputs such as graphs, tables, statistical plots/charts and maps | YES | See Section 3.3 | Public Health Services & Consultancy | Pending Market Study | Commercial Exploitation license granted | Software own by echo partners and csisp according to their respective share |
| | | | | | | | |

3.2 ECHO tool software

3.2.1 Introduction

One of the deliverables of the ECHO project is the “web based analytical tools” (i.e. the ECHO tool, Deliverable 4) that allow users to apply, in a friendly manner, all ECHO methodological developments and analyses implemented, and provides dynamic analytical (ad hoc) reports through the ECHO webpage <http://www.echo-health.eu/>.

The ECHO tool software allows users to calculate dynamically analytical variables, to process and summarise the data in real time and to generate outputs in the form of onscreen (and downloadable) graphs, tables, statistical plots/charts and maps.

Using this ECHO tool software, online users accessing through the ECHO webpage <http://www.echo-health.eu/> will perform comparisons between and within English, Danish, Portuguese, Slovenian, Austrian and Spanish regions, countries and hospitals.

3.2.2 Origin of the ECHO tool software (Access rights from “Atlas VPM eTOOLS”)

The ECHO tool software is adapted from the Atlas VPM eTOOLS software owned by IACS/CSISP.

According to section 8.4.2 of the ECHO Consortium Agreement, the access rights to intellectual property rights held by beneficiaries prior to their accession to the ECHO Project shall be granted to other beneficiaries if needed to develop the ECHO Project. To this end, a licence of use agreement is signed between IACS, IVZ and the other project partners.

The programming of the ECHO tool software is carried out by Comex, the company that has been awarded the tender launched by IVZ. As of the date of payment, all material resulting in connection with the contract between IVZ and Comex (applications, tools, documents, etc) shall become the exclusive and unlimited property of the owners of this Foreground (including the right to process, after-treatment, distribution, copying, transfer to another platform or another person the use of a part of the code in other applications).

3.2.3 Ownership of the ECHO tool software

According to section 8.1 of the ECHO Consortium Agreement, the parties shall agree amongst themselves the allocation and terms of exercising ownership of the Foreground of the ECHO project. Each party share of the ECHO tool will be proportional to their contribution to the development of the ECHO tool.

As the ECHO tool software will be an adaptation of the Atlas VPM eTOOLS software, upon consultation with the ECHO partners:

- the main portion (75%) on the ownership of the ECHO tool software will be for IACS/CSISP as co-owners of the Atlas VPM eTOOLS software.
- The remaining 25% has been be allocated according to the person/month distribution in Work Package 4 as included in Annex I of the Grant Agreement n° 242189, as follows:

| | |
|------------|----|
| 1. IACS | 2% |
| 2. ENSP | 4% |
| 3. IVZ | 9% |
| 4. UYORK | 3% |
| 5. UMIT | 3% |
| 6. SAM_SDU | 3% |
| 7. EHMA | 1% |

NB: Although not granted by the person/month distribution in WP4, EHMA receives a portion in consideration of its specific role in the dissemination of the ECHO project.

3.2.4 Commercial exploitation of the ECHO tool software

In order to allow IACS to be able to exploit commercially the ECHO tool software, it is envisaged that the ECHO tool software shareholders will grant IACS exclusive rights to exploit commercially the ECHO tool software. Co-owners will be informed and ask to comment prior to any commercial activity taken place.

IACS will distribute, in proportion to the share of ownership, the eventual net economic benefit derived from such exploitation among the shareholders.

3.2.5 Access to the ECHO tool for third parties

EHMA and IACS have drawn up terms of agreement for third parties to agree with when accessing and using the ECHO tool, with the aim of decreasing the risk of abuse of the tool. The terms can be found in Annex 1.

3.3 Website, handbook of methodology and atlases

The website, handbook of methodology and atlases are important public dissemination channels for the ECHO project. EHMA is the responsible party for the updating of the website (task 5.1), within the framework delivered by IVZ. In addition, EHMA is in charge of the planning and delivery of electronic access to the evidence produced by the project – shaped as the online handbook of methodology and atlases. However these activities are resource intensive and cannot be continued after the lifetime of the project without adequate funding.

In line with the consortium agreement, the foreground remains with the producing (partner(s)). This means that project partners need other partners' agreement on the use of foreground when they want to use it after the project is terminated. This is also the case when the CA is extended.

When the project is finished (post February 2014) and if updates of the website or related platforms are required, the project coordinator will contact EHMA and provide the content on behalf of the consortium. These updates should be possible to make within the framework of the content-management system.

4. Future project opportunities and related funding opportunities

This section outlines opportunities for continuing the work started by the ECHO project. The next section explores practical ways on how the ECHO consortium can increase the interest of EU Member States, in order to improve the sustainability of the project. Secondly, this chapter covers a number of (EU) funding opportunities, including how the results of ECHO can be used for different means (e.g. better use in policy decisions, further research). Lastly, the third section presents the conclusions from discussions within the consortium about the advantages and disadvantages on charging parties for the delivery of aggregated data.

4.1 Building further interest with EU Member States

In a time when the (financial) sustainability of health systems and the quality and safety of provided services are on top of the EU health agenda, the ECHO project is in the position to deliver valuable evidence for policy decision making. There are a number of opportunities to increase knowledge of the tool and its possibilities to Member States. Key forums are the European Commission DG SANCO Patient Safety and Quality of Care Working Group, the high level reflection process, and in particular the working group on sustainable health systems. The ECHO project was also presented at the European Health Forum Gastein to extend its reach to high-level policy makers.

Through the Local Dissemination Groups and a future Policy Dialogue (planned for spring 2014) the project has created interests throughout the system, with the Policy Dialogues having the particular aim to inform high-level policy makers of the potential of ECHO in addressing systematic variation.

4.2 EU funding opportunities

4.2.1 COST Framework

COST (European Cooperation in Science and Technology) is a European framework supporting cooperation among scientists and researchers across Europe – it aims at the coordination of nationally-funded research on a European level. The features of the programme are (1) building capacity by connecting high-quality scientific communities throughout Europe and worldwide; (2) providing networking opportunities for early career investigators; and (3) increasing the impact of research on policy makers, regulatory bodies and national decision makers as well as the private sector. The domain *Individuals, Societies, Cultures and Health* (ISCH) supports the development of knowledge and insights for citizens, democratic debate and decision-making in the public, private and voluntary spheres.

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COST funding covers cover the costs of networking activities such as meetings (e.g. travel, subsistence, local organiser support), conferences, workshops, short-term scientific exchanges, training schools, publications and dissemination activities. COST does not fund the research itself, which would have to be covered by participating universities and research centers themselves. The minimum number of countries to participate in an action is 5 but the average number of countries participating in financed actions is 20 and the average grant per action is 130 000 Euros.

In September 2012 the ECHO consortium and other potential partners submitted a proposal entitled *The European Collaboration for Health Optimisation plus Action* (ECHOplus Action). The proposal aimed at consolidating and expanding the ECHO network, fostering joint research collaboration towards a self sustained Europe-wide knowledge system on unwarranted variations in medical practice and healthcare outcomes – entailing data pooling, methodology sharing and knowledge transferring to decision makers across European countries and umbrella organizations.

Conceived as a pilot study, ECHO has focused on building a massive database (more than 200 Million individual patient discharges from 6 countries), fine-tuning methods of analysis, measuring the actual performance of the participant countries and it is currently developing an interface that mines into the database to return sound information about unwarranted variation over time and across countries/regions. The research network could therefore start its research using the wealth of resources delivered by the ECHO project, and has the potential to build an exchange network enabling members the study of unwarranted variation in performance implementing the ECHO methods into more healthcare systems. Additional participating countries in the extended network include Belgium, France, Hungary, Italy, the Netherlands, and Switzerland. As such, such network would build the capacity of high-quality scientific communities in Europe.

The evaluation of the first proposal noted that ECHOplus is “[An] interesting proposal aiming at consolidation and expansion of the ECHO network, fostering joint research collaboration towards a self sustained European-wide knowledge system. Transferring knowledge to decision makers across European countries is important but should be better explained.” The report also indicated that the proposal needs more focus and coherency, and an increased number of deliverables.

The second review emphasised that the proposal is interesting, but that a number of clarifications are required. These include: how the network would function from a methodological perspective; deliverables need further clarification; the added value of transnational cooperation in the field; and how different countries and disciplines would be involved in the network.

4.2.2 Public Health Programme – Joint Action

Joint Actions are activities carried out by the European Union and one or more Member States or by the EU and the competent authorities of other countries participating in the Public Health Programme together. *Joint Action* could therefore be described as ‘projects with EU Member States’ assuring Member States’ support and involvement in the activities, and their funding as well. Joint Actions offer the opportunity for Member States to tackle challenges on Member State level, possibly with instruments that provide an EU-added value.

A Joint Action would offer the opportunity of having many EU Member States involved, and committed to delivering the necessary up-to-date data sets. Though Joint Actions are generally not focused on research, a research-like component could be included. However the involvement of current members of the project consortium could not be guaranteed.

Ideally in cooperation with DG SANCO, the project consortium will explore the opportunities of bringing the possibilities of an ‘ECHO Joint Action’ to the agenda. The Italian Presidency (second half of 2014) is identified as providing a window of opportunity to bring this to member states’ agendas.

4.2.3 Horizon 2020

The Horizon 2020 research programme would be a logical source of funding to continue the work started in the ECHO project. This new research programme does not only include the follow-up to the 7th Framework Programme, but also the Competitiveness Innovation Programme (CIP) and the EU contribution to the European Institute of Innovation and Technology (EIT). Funding for Health, demographic change and wellbeing is expected to be little more than 8 billion for the next 7 years.

Within the framework of this programme ECHO could continue its research activities, further optimise the working of the Data Warehouse and work on the methodologies that are currently developed. However, a key issue is acquiring up-to-date patient-level data, which would require approval from competent authorities in the involved Member States – difficulties are expected. In addition, uptake and use for decision making is not guaranteed.

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4.2.4. Summarising overview and self-listed pros and cons

| Programme | Research opportunities | Impact on practice | Securing MS involvement and datasets | Financial attractiveness | Other comments | Assessment |
|--------------|------------------------|--------------------|--------------------------------------|--------------------------|---|--|
| COST Network | + | - | +/- | - | | <p>Excellent instrument to support the networking of research groups that are funded otherwise, and that have the availability of access to existing data sets.</p> <p>Though not easy to achieve funding, the interest is there.</p> |
| Joint Action | +/- | ++ | ++ | - | <p>Likely occurrence of time lag between the ECHO project and possible start of a JA.</p> | <p>JA is likely to build in Member States' commitment and the necessary data sets. Increased policy impact may be expected, but Joint Actions are not a funding instrument for research.</p> <p>Making it happen is a difficult political process. However if it would be agreed that such network would provide added value to Member States there would be no competition for funding.</p> |

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| | | | | | | |
|-------------|----|-----|-----|---|--|---|
| Horizon2020 | ++ | +/- | +/- | + | <p>The project would apply following an open call, and would be subject to heavy competition.</p> <p>The focus would be on improving research, not policy decision making.</p> | <p>Horizon 2020 would be the ideal funding mechanism to further improve methodologies and the function of the DWH infrastructure, however it might be difficult acquiring the data from each involved Member State.</p> |
|-------------|----|-----|-----|---|--|---|

4.3 Opportunities outside EU funding frameworks – commercial exploitation of the ECHO infrastructure

4.3.1. Delivering aggregated data

During the last project meeting in Copenhagen the consortium extensively discussed the possibilities, advantages and disadvantages of charging for the delivery of aggregated data.

Possible positive effects of delivering aggregated data to other parties include:

4. Could create some finance to continue ECHO work as well as covering costs
5. Could ensure that ECHO data is used to improve healthcare in countries
6. Could raise the profile of ECHO so potentially attracting more funding/avenues of funding

However, the discussion reflected a range of technical/practical and ethical issues:

5. All partners need to agree to collect and analyse data on a yearly basis. Outdated data is likely to be uninteresting for decision making
6. Requires cooperation of all partner countries for European comparison
7. The ethical clearance for countries may not allow for 'sale' of data; at the moment of writing a heated discussion takes place in England¹⁴ about the availability of pseudonymised data to private companies including the pharmaceutical industry
8. The rules on destruction of data by a certain date for some countries means that longitudinal data may not be available decreasing the attractiveness of what could be on offer
9. It is not clear that the costs of collecting/analysing data could be covered by sale (including necessary back-room staff)

The shared view of the consortium was that the offer would be very limited, in particular taking note of the technical and ethical clearances involved.

¹⁴ "Better information means better care", page available at <http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/care-data.aspx>. Last accessed on 12/02/2014

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4.3.2. Exploitation of the ECHO tool

In addition to the data, there is the opportunity to explore commercial exploitation of the methodology and technical infrastructure behind the ECHO tool. However there is and always has been reservations about this approach, in particular due to the public nature of the project's funding and the private nature of the data involved. However, the consortium would applaud the uptake of the tool by European Member States and other bodies of a public nature.

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Annex 1: Disclaimer for the ECHO tool

AUTHORISATION AGREEMENT

TERMS AND CONDITIONS OF USE

Acknowledgement and acceptance

Read this carefully before using the ECHO Tool (also referenced to as 'the Tool'). By utilising the Tool the user hereby accepts all of the terms and conditions of this agreement.

Access to the ECHO Tool

Access to and use of the ECHO Tool is on personal title, and limited to the entitled person only. Sharing of access codes is forbidden, and the entitled user is responsible for maintaining the confidentiality of the password and ID as specified in the registration process.

1. Definitions

“ECHO software”: shall mean the software that allows online users to calculate the ECHO indicators in real time and to generate outputs in the form of onscreen (and downloadable) graphs, tables, statistical plots/charts and maps which allow comparisons to be made between and within Spanish, Portuguese, English, Slovene and Danish regions and hospitals.

“ECHO Data Warehouse” shall mean the database of all partners’ raw data concerning each party’s national healthcare system, standardized to fit the ECHO Data base specifications.

“ECHO Tool”: shall mean the web tool, the ECHO Software and the ECHO Data Warehouse together.

“Content”: shall mean all the summary statistics (including text, graphs, tables, statistical plots/charts, maps etc) generated by the ECHO Tool.

“User”: shall have the meaning of researcher, health manager, policy maker or any other healthcare stakeholder working in public institutions entitled through the signature of this agreement and completion of the registration process to use the ECHO Tool.

2. ECHO tool usage

Access to and use of the ECHO Tool is provided free of charge on the following address: <http://www.echo-health.eu/?site=echotool> on personal title, and limited to the entitled person only. The user will be required to create a user account in order to access the services offered by the ECHO Tool.

3. Access to the ECHO Tool

User requirements

The User agrees to use the ECHO Tool and its Content only to obtain scientific insights to support research and/or decision-making linked to the User's professional activities. Reproduction, distribution, transmission, re-publication, display or performance, of the Content delivered by the ECHO Tool shall acknowledge the source.

User is responsible to maintain the confidentiality of its password and ID.

User agrees not to use the interface in any way adversely affects the performance or function of the server or the performance of the ECHO Tool;

Usage restrictions

The User warrants that s/he will not, nor will they license or permit others to, directly or indirectly:

Sell, distribute, license, rent or otherwise exploit the ECHO Tool and/or its Content or any element of it, for any commercial purposes.

Post or transmit information or materials that would violate the rights of the ECHO software or the datasets owners (for instance, package software which contains a virus or other harmful component that alters, amends, modifies, translates, or changes the ECHO Software and/or the Content).

Otherwise use the material supplied in accordance with this Agreement in a manner that would infringe this Agreement.

Intellectual Property Rights

The ECHO Software used on this site is co-owned by the ECHO Consortium members and La Fundación para el Fomento de la Investigación Sanitaria y Biomédica de la Comunitat Valenciana FISABIO. The Content includes data from national datasets, which belongs to specific national authorities.

National datasets are used with permission from its owners.

Both the ECHO Software and the Content are protected by national and international copyright laws.

Limitation of liability

The ECHO Consortium strives to keep the Content, complete, up-to-date and accurate according to rigorous professional standards.

Under no circumstances, including but not limited to negligence, will the ECHO Software owners or the national institutions providing the national datasets be liable for any sort of damages that result from the use or inability to use the materials produced by the ECHO Tool.

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Jurisdiction

This Agreement shall be construed and controlled by the laws of Spain, and in the exclusive jurisdiction of the courts sitting in the city of Zaragoza.

Termination

The ECHO Software owners may terminate the supply of the content at any time upon written notice posted at the ECHO website. On termination of the supply, the user shall have no rights of any kind.

I acknowledge, I have read, and understand the above terms and conditions and I accept this authorisation agreement by [CLICKING HERE](#)

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Annex 2: ECHO tool software and commercial licence partners draft agreement

ECHO TOOL SOFTWARE

JOINT OWNERSHIP ACCESS RIGHTS AND LICENCE AGREEMENT

THIS JOINT OWNERSHIP, ACCESS RIGHTS AND LICENCE AGREEMENT (hereinafter, referred to as the "Agreement") is made and entered into force as of the later of the signature dates below (hereinafter, referred to as the "Effective Date") by and between:

INSTITUTO ARAGONÉS DE CIENCIAS DE LA SALUD (hereinafter, referred to as "IACS"), with principal offices located at Av. San Juan Bosco 13, Zaragoza 50009, Spain, C.I.F. number Q-5000654-C, hereby represented by Luis Rosel Onde, duly empowered to enter into this Agreement and to represent said entity;

FUNDACION PARA EL FOMENTO DE LA INVESTIGACION SANITARIA Y BIOMEDICA DE LA COMUNITAT VALENCIANA (hereinafter, referred to as "FISABIO"), with principal offices located at Avda. Catalunya nº 21, 46020 Valencia, Spain C.I.F. number Q4601185D, hereby represented by Andres Moya Simarro, duly empowered to enter into this Agreement and to represent said entity;

ESCOLA NACIONAL DE SAUDADE PÚBLICA, - UNIVERSIDADE NOVA DE LISBOA (hereinafter, referred to as "ENSP"), with principal offices located at Avenida Padre Cruz, Lisboa, 1600 560, Portugal, legal number 501399003, hereby represented by Constantino Sakellarides, duly empowered to enter into this Agreement and to represent said entity;

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NATIONAL INSTITUTE OF PUBLIC HEALTH (hereinafter, referred to as “NIJZ”), with principal offices located at Trubarjeva cesta 2, Ljubljana, SI-1000, legal registration number 6462642000, hereby represented by Ivan Erzen, duly empowered to enter into this Agreement and to represent said entity;

THE UNIVERSITY OF YORK (hereinafter, referred to as “UYORK”), with principal offices located at Heslington Hall, York, Yo10 5DD, legal registration number RC000679, hereby represented by Heather Watson, duly empowered to enter into this Agreement and to represent said entity;

PRIVATE UNIVERSITY FOR HEALTH SCIENCES, MEDICAL INFORMATICS AND TECHNOLOGY (hereinafter, referred to as “UMIT”), with principal offices located at Eduard Wallnoefer, Zentrum 1, hall in Tirol 6060, Austria, legal registration number FN215003G, hereby represented by Christa Them, duly empowered to enter into this Agreement and to represent said entity;

UNIVERSITY OF SOUTHERN DENMARK – INSTITUTE OF PUBLIC HEALTH, HEALTH ECONOMICS (hereinafter, referred to as “SAM_SDU”), with principal offices located at Campusvej 55, Odense M, 5230, Denmark, legal registration number 29283958, hereby represented by Lars Stig Moeller, duly empowered to enter into this Agreement and to represent said entity;

EUROPEAN HEALTH MANAGEMENT ASSOCIATION LIMITED (hereinafter, referred to as “EHMA”), with principal offices located at Rock road 118, Booterstown Dublin, Ireland, legal representation number, 477611/CHY6356 hereby represented by Jeni Bremner, duly empowered to enter into this Agreement and to represent said entity.

RECITALS

Whereas, the ECHO partners are beneficiaries of the Grant Agreement n° 242189 of the 7th Framework Programme for the Collaborative Project entitled ECHO (European Collaboration for Healthcare Optimization) (hereinafter, referred to as the “ECHO Project”), which aims at describing the actual performance of six different healthcare systems and includes different academic and research institutions from six European countries and an European Health Management Association.

i. Whereas, one of the Deliverables of the ECHO Project is the “web-based analytic tools” (Deliverable 4) (hereinafter, referred to as the “ECHO tool”) that allows users to use, in a friendly manner, all methodological developments and analyses implemented, and provides dynamic analytical (ad hoc) reports.

ii. Whereas, in the development of the ECHO Project and in order to create the ECHO tool, the above parties are jointly developing a database (hereinafter, referred to as the “ECHO DWH”) and the “ECHO tool” software (hereinafter, referred to as the “Software”).

iii. Whereas, the ECHO DWH is a database of all partners’ raw data concerning each party’s national healthcare system.

iv. Whereas, the Software is an adaptation of the Atlas VPM eTools software owned by IACS and CSISP that allows dynamic analytical (ad hoc) reports of the data stored in the ECHO DWH.

v. Whereas, the Software, the ECHO DWH and the ECHO tool constitute a foreground of the ECHO Project (hereinafter, referred to as “Foreground”), understood as the results, including information, whether or not they can be protected, which are generated in the ECHO Project (including rights related to copyright design rights patent rights or similar forms of protection).

vi. Whereas, according to section 8.1 of the ECHO Consortium Agreement (hereinafter, referred to as the “Consortium Agreement) the parties shall agree amongst themselves the

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vii. allocation and terms of exercising the ownership of the jointly owned Foreground, and to determine the access rights to that Foreground herein mentioned.

viii. Whereas, the above parties have decided to agree the allocation and terms of exercising the ownership of the jointly owned Software and to grant IACS an exclusive exploitation right of this Software.

Now therefore, in consideration of the mutual covenants and agreements hereinafter set forth, the parties hereto agree to enter into this Agreement subject to the following

COVENANTS

1. SUBJECT

This Agreement defines the allocation of ownership of the Software, the Access rights to the Software and the granting of exploitation rights of the Software to IACS.

2. INTRODUCTION

The Software will allow users to calculate dynamically analytical variables, to process and summarise the data in real time and to generate outputs in the form of onscreen (and downloadable) graphs, tables, statistical plots/charts and maps.

In the case of the ECHO Project, using the Software, online users accessing through the ECHO webpage <http://www.echo-health.eu/> will perform comparisons between and within English, Danish, Portuguese, Slovenian, Austrian and Spanish geographical areas.

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3. ORIGIN OF THE SOFTWARE

The Software is an adaptation from the Atlas VPM eTools software owned by IACS and FISABIO.

According to section 8.4.2 of the Consortium Agreement, the access rights to intellectual property rights held by the parties prior to their accession to the ECHO Project shall be granted to other parties if needed to develop the ECHO Project. To this end, a license of use agreement was signed between IACS and IVZ on 18.01.2013.

The Software has been delivered by Hiberus Tecnologia, S.L., c/ Bari 25 Duplicado 50197, Zaragoza, Spain, the company that was awarded the tender launched by IVZ (*public procurement procedure for the Development of an online analysis interface to a large medical database with reference number 14/11-JN, published on the <http://www.e-narocanje.si> portal on 16.02.2012 under Notice number JN1774/2012*). As of the date of payment, all material resulting in connection with the contract between IVZ and Hiberus Tecnologia (applications, tools, documents, etc) become the exclusive and unlimited property of the owners of this Software in the proportion allocated in this Agreement.

4. OWNERSHIP OF THE SOFTWARE

According to section 8.1 of the Consortium Agreement, each party share of the Software will be proportional to their contribution to its development.

IACS and FISABIO, as co-owners of the Atlas VPM eTools software, will jointly hold 75% of the Software ownership, allocated according to their respective ownership of the Atlas VPM eTools software.

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The remaining 25% will be allocated according to the person/month distribution in Work Package 4 as included in Annex I of the Grant Agreement n° 242189, as follows:

| | |
|------------|----|
| 1. IACS | 2% |
| 2. ENSP | 4% |
| 3. IVZ | 9% |
| 4. UYORK | 3% |
| 5. UMIT | 3% |
| 6. SAM_SDU | 3% |
| 7. EHMA | 1% |

5. ACCESS RIGHTS TO THE SOFTWARE

The parties agree to confer access rights to the Software to IACS for software improvement reasons and/or its exploitation by means of Covenant 6.

Access rights to the Software shall be granted to the other co-owners only for software improvement reasons, when decided by the co-owners by qualified majority.

6. EXPLOITATION OF THE SOFTWARE

In order to allow IACS to exploit the Software, including the granting of licenses to the software to third parties, the Software co-owners grant IACS an exclusive right to exploit it, without prejudice to the provisions of Covenant 5. These exclusive rights refer only to the Software and not to the ECHO DWH.

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IACS shall be responsible for maintaining and prosecuting, on behalf of all parties and co-owners of the Software, of any intellectual property rights over the Software. However, each party shall be entitled to exercise any rights or actions in defence of the Software and/or any other intellectual property rights.

Joint owners shall contribute to, in portion to their share of the Software, all costs of obtaining and maintaining any intellectual property rights over the Software.

IACS will distribute among co-owners, in portion to the ownership share of each party, the eventual net economic benefit derived from the exploitation of the Software..

The parties agree to maintain their participation on the Software as stated in section 4 of this Agreement during the development of the ECHO Project. Any reallocation of the parties' shares shall be decided by the majority of the parties.

7. NON DISCLOSURE AGREEMENT

The parties expressly undertake to keep confidential all information, facts and know-how disclosed. Without limiting the foregoing, all terms and conditions of this Agreement shall be considered confidential and shall not be disclosed (except to each party's attorneys and accountants on a need-to-know basis) without the prior written consent of the other parties.

This non disclosure provision will survive termination or expiration of this License Agreement.

7. TERM, TERMINATION AND SURVIVAL

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This Agreement shall enter into force since the Effective Date and will continue in force until the moment when the Software enters the public domain. At that moment, the licence granted will expire.

This Agreement may be terminated by any party for a material breach of any material term that is not cured within thirty (30) days after written notice thereof from the party alleging such a breach.

9. GOVERNING LAW, JURISDICTION AND LANGUAGE

This Agreement shall be construed and controlled by the laws of Spain, and to exclusive jurisdiction by the courts sitting in the city of Zaragoza.

This Agreement is executed in the English language which shall be the sole and controlling language used in interpreting or construing its meaning.

10. NOTICES AND REQUESTS

All notices and requests in connection with this Agreement shall be deemed given as of the day they are (i) deposited in mails, postage prepaid, certified or registered, return receipt requested; or (ii) sent by overnight courier, charges prepaid, with a confirming fax; and addressed to the addresses set forth above, or to such other address as the party to receive the notice or request so designates by written notice to the other.

11. LEGAL RELATIONSHIP

This Agreement is intended solely as a joint ownership, access rights and licence agreement, and no partnership, joint venture, employment, agency, franchise, or other form of agreement or relationship is intended.

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12. SEVERABILITY

In the event that any provision of this Agreement is found invalid or unenforceable pursuant to judicial decree or decision, the remainder of this Agreement shall remain valid and enforceable according to its terms. The parties intend that the provisions of this Agreement be enforced to the fullest extent permitted by applicable law. Accordingly, the parties agree that if any provisions are deemed not enforceable, they shall be deemed modified to the extent necessary to make them enforceable.

13. ENTIRE AGREEMENT/MODIFICATION/OFFER

The parties hereto agree that this Agreement constitutes the entire agreement between the parties with respect to the subject matter hereof and merges all prior and contemporaneous communications. It shall not be modified except by a written agreement dated subsequent hereto signed on behalf of each party by their duly authorized representatives. Neither this Agreement nor any written or oral statements related hereto constitute an offer, and this Agreement shall not be legally binding until executed by the parties hereto.

14. BINDING EFFECT

This Agreement may not be assigned in whole or in part by the parties. Except as otherwise provided, this Agreement will inure to the benefit of, and be binding upon the parties, their successors, administrators, heirs, and permitted assigns.

IN WITNESS WHEREOF, the parties hereto have caused this Agreement to be executed as of the Effective Date.

4.3 Report on societal implications

Replies to the following questions will assist the Commission to obtain statistics and indicators on societal and socio-economic issues addressed by projects. The questions are arranged in a number of key themes. As well as producing certain statistics, the replies will also help identify those projects that have shown a real engagement with wider societal issues, and thereby identify interesting approaches to these issues and best practices. The replies for individual projects will not be made public.

| A General Information (completed automatically when <i>Grant Agreement number</i> is entered.) | |
|---|--|
| Grant Agreement Number: | 242189 |
| Title of Project: | European Collaboration for Healthcare Optimization |
| Name and Title of Coordinator: | Dr. Enrique Bernal-Delgado |
| B Ethics | |
| 1. Did your project undergo an Ethics Review (and/or Screening)? <ul style="list-style-type: none"> If Yes: have you described the progress of compliance with the relevant Ethics Review/Screening Requirements in the frame of the periodic/final project reports? <p>Special Reminder: the progress of compliance with the Ethics Review/Screening Requirements should be described in the Period/Final Project Reports under the Section 3.2.2 'Work Progress and Achievements'</p> | Yes <u>No</u> |
| 2. Please indicate whether your project involved any of the following issues (tick box) : | YES |
| RESEARCH ON HUMANS | |
| • Did the project involve children? | |
| • Did the project involve patients? | |
| • Did the project involve persons not able to give consent? | |
| • Did the project involve adult healthy volunteers? | |
| • Did the project involve Human genetic material? | |
| • Did the project involve Human biological samples? | |
| • Did the project involve Human data collection? | |
| RESEARCH ON HUMAN EMBRYO/FOETUS | |
| • Did the project involve Human Embryos? | |
| • Did the project involve Human Foetal Tissue / Cells? | |
| • Did the project involve Human Embryonic Stem Cells (hESCs)? | |
| • Did the project on human Embryonic Stem Cells involve cells in culture? | |
| • Did the project on human Embryonic Stem Cells involve the derivation of cells from Embryos? | |
| PRIVACY | |
| • Did the project involve processing of genetic information or personal data (eg. health, sexual lifestyle, ethnicity, political opinion, religious or philosophical conviction)? | X |
| • Did the project involve tracking the location or observation of people? | |
| RESEARCH ON ANIMALS | |
| • Did the project involve research on animals? | |

| | |
|---|---------------|
| • Were those animals transgenic small laboratory animals? | |
| • Were those animals transgenic farm animals? | |
| • Were those animals cloned farm animals? | |
| • Were those animals non-human primates? | |
| RESEARCH INVOLVING DEVELOPING COUNTRIES | |
| • Did the project involve the use of local resources (genetic, animal, plant etc)? | |
| • Was the project of benefit to local community (capacity building, access to healthcare, education etc)? | |
| DUAL USE | |
| • Research having direct military use | Yes <u>No</u> |
| • Research having the potential for terrorist abuse | |

C Workforce Statistics

3. Workforce statistics for the project: Please indicate in the table below the number of people who worked on the project (on a headcount basis).

| Type of Position | Number of Women | Number of Men |
|---|-----------------|---------------|
| Scientific Coordinator | 0 | 1 |
| Work package leaders | 2 | 4 |
| Experienced researchers (i.e. PhD holders) | 4 | 7 |
| PhD Students | 2 | 2 |
| Other | 2 | 4 |
| 4. How many additional researchers (in companies and universities) were recruited specifically for this project? | 5 | |
| Of which, indicate the number of men: | 3 | |

D Gender Aspects

5. Did you carry out specific Gender Equality Actions under the project? No

6. Which of the following actions did you carry out and how effective were they?

| | Not at all effective | Very effective |
|---|---|-----------------------|
| <input type="checkbox"/> Design and implement an equal opportunity policy | <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> | <input type="radio"/> |
| <input type="checkbox"/> Set targets to achieve a gender balance in the workforce | <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> | <input type="radio"/> |
| <input type="checkbox"/> Organise conferences and workshops on gender | <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> | <input type="radio"/> |
| <input type="checkbox"/> Actions to improve work-life balance | <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> | <input type="radio"/> |
| <input type="radio"/> Other: <input type="text"/> | | |

7. Was there a gender dimension associated with the research content – i.e. wherever people were the focus of the research as, for example, consumers, users, patients or in trials, was the issue of gender considered and addressed?

The research included access to and safety of healthcare procedures with a gender dimension, e.g. caesarean sections.

Yes- please specify

E Synergies with Science Education

8. Did your project involve working with students and/or school pupils (e.g. open days, participation in science festivals and events, prizes/competitions or joint projects)?

No

9. Did the project generate any science education material (e.g. kits, websites, explanatory booklets, DVDs)?

The project produced a handbook on methodologies, which is accessible to all on www.echo-health.eu

Yes- please specify

F Interdisciplinarity

10. Which disciplines (see list below) are involved in your project?

- Main discipline¹⁵: 3.3
 Associated discipline¹⁵:

G Engaging with Civil society and policy makers

11a Did your project engage with societal actors beyond the research community? (if 'No', go to Question 14)

No

11b If yes, did you engage with citizens (citizens' panels / juries) or organised civil society (NGOs, patients' groups etc.)?

No

11c In doing so, did your project involve actors whose role is mainly to organise the dialogue with citizens and organised civil society (e.g. professional mediator; communication company, science museums)?

No

12. Did you engage with government / public bodies or policy makers (including international organisations)

- Yes- in framing the research agenda
 Yes - in implementing the research agenda
 Yes, in communicating /disseminating / using the results of the project

13a Will the project generate outputs (expertise or scientific advice) which could be used by policy makers?

Yes – as a **primary** objective (please indicate areas below- multiple answers possible)

13b If Yes, in which fields?

| | | |
|---|---|--|
| Agriculture Audiovisual and Media Budget Competition Consumers Culture Customs Development Economic and Monetary Affairs Education, Training, Youth Employment and Social Affairs | Energy Enlargement Enterprise Environment External Relations External Trade Fisheries and Maritime Affairs Food Safety Foreign and Security Policy Fraud Humanitarian aid | Human rights Information Society Institutional affairs Internal Market Justice, freedom and security <u>Public Health</u> <u>Regional Policy</u> <u>Research and Innovation</u> Space Taxation Transport |
|---|---|--|

¹⁵ Insert number from list below (Frascati Manual).

13c If Yes, at which level?

- Local / regional levels
- National level
- European level

H Use and dissemination

14. How many Articles were published/accepted for publication in peer-reviewed journals?

1

To how many of these is open access¹⁶ provided?

1

How many of these are published in open access journals?

0

How many of these are published in open repositories?

0

To how many of these is open access not provided?

Please check all applicable reasons for not providing open access:

- publisher's licensing agreement would not permit publishing in a repository
- no suitable repository available
- no suitable open access journal available
- no funds available to publish in an open access journal
- lack of time and resources
- lack of information on open access
- other¹⁷:

15. How many new patent applications ('priority filings') have been made?
("Technologically unique": multiple applications for the same invention in different jurisdictions should be counted as just one application of grant).

0

16. Indicate how many of the following Intellectual Property Rights were applied for (give number in each box).

Trademark

0

Registered design

0

Other

0

17. How many spin-off companies were created / are planned as a direct result of the project?

0

Indicate the approximate number of additional jobs in these companies:

18. Please indicate whether your project has a potential impact on employment, in comparison with the situation before your project:

- | | |
|---|---|
| <input type="checkbox"/> Increase in employment, or | <input type="checkbox"/> In small & medium-sized enterprises |
| <input type="checkbox"/> Safeguard employment, or | <input type="checkbox"/> In large companies |
| <input type="checkbox"/> Decrease in employment, | <input checked="" type="checkbox"/> None of the above / not relevant to the project |

¹⁶ Open Access is defined as free of charge access for anyone via Internet.

¹⁷ For instance: classification for security project.

| | | | |
|--|---|-------------------------------------|---|
| <input type="checkbox"/> | Difficult to estimate / not possible to quantify | | |
| 19. | For your project partnership please estimate the employment effect resulting directly from your participation in Full Time Equivalent (FTE = one person working fulltime for a year) jobs: | <i>Indicate figure:</i> 20 | |
| | Difficult to estimate / not possible to quantify | | <input type="checkbox"/> |
| I Media and Communication to the general public | | | |
| 20. | As part of the project, were any of the beneficiaries professionals in communication or media relations? | | |
| | <input checked="" type="radio"/> No | | |
| 21. | As part of the project, have any beneficiaries received professional media / communication training / advice to improve communication with the general public? | | |
| | <input checked="" type="radio"/> No | | |
| 22 | Which of the following have been used to communicate information about your project to the general public, or have resulted from your project? | | |
| <input checked="" type="checkbox"/> | Press Release | <input type="checkbox"/> | Coverage in specialist press |
| <input type="checkbox"/> | Media briefing | <input type="checkbox"/> | Coverage in general (non-specialist) press |
| <input checked="" type="checkbox"/> | TV coverage / report | <input type="checkbox"/> | Coverage in national press |
| <input type="checkbox"/> | Radio coverage / report | <input type="checkbox"/> | Coverage in international press |
| <input checked="" type="checkbox"/> | Brochures /posters / flyers | <input checked="" type="checkbox"/> | Website for the general public / internet |
| <input type="checkbox"/> | DVD /Film /Multimedia | <input type="checkbox"/> | Event targeting general public (festival, conference, exhibition, science café) |
| 23 | In which languages are the information products for the general public produced? | | |
| <input type="checkbox"/> | Language of the coordinator | <input checked="" type="checkbox"/> | English |
| <input type="checkbox"/> | Other language(s) | | |

Question F-10: Classification of Scientific Disciplines according to the Frascati Manual 2002 (Proposed Standard Practice for Surveys on Research and Experimental Development, OECD 2002):

FIELDS OF SCIENCE AND TECHNOLOGY

1. NATURAL SCIENCES

- 1.1 Mathematics and computer sciences [mathematics and other allied fields: computer sciences and other allied subjects (software development only; hardware development should be classified in the engineering fields)]
- 1.2 Physical sciences (astronomy and space sciences, physics and other allied subjects)
- 1.3 Chemical sciences (chemistry, other allied subjects)
- 1.4 Earth and related environmental sciences (geology, geophysics, mineralogy, physical geography and other geosciences, meteorology and other atmospheric sciences including climatic research, oceanography, vulcanology, palaeoecology, other allied sciences)

- 1.5 Biological sciences (biology, botany, bacteriology, microbiology, zoology, entomology, genetics, biochemistry, biophysics, other allied sciences, excluding clinical and veterinary sciences)

2. ENGINEERING AND TECHNOLOGY

- 2.1 Civil engineering (architecture engineering, building science and engineering, construction engineering, municipal and structural engineering and other allied subjects)
- 2.2 Electrical engineering, electronics [electrical engineering, electronics, communication engineering and systems, computer engineering (hardware only) and other allied subjects]
- 2.3. Other engineering sciences (such as chemical, aeronautical and space, mechanical, metallurgical and materials engineering, and their specialised subdivisions; forest products; applied sciences such as geodesy, industrial chemistry, etc.; the science and technology of food production; specialised technologies of interdisciplinary fields, e.g. systems analysis, metallurgy, mining, textile technology and other applied subjects)

3. MEDICAL SCIENCES

- 3.1 Basic medicine (anatomy, cytology, physiology, genetics, pharmacy, pharmacology, toxicology, immunology and immunohaematology, clinical chemistry, clinical microbiology, pathology)
- 3.2 Clinical medicine (anaesthesiology, paediatrics, obstetrics and gynaecology, internal medicine, surgery, dentistry, neurology, psychiatry, radiology, therapeutics, otorhinolaryngology, ophthalmology)
- 3.3 Health sciences (public health services, social medicine, hygiene, nursing, epidemiology)

4. AGRICULTURAL SCIENCES

- 4.1 Agriculture, forestry, fisheries and allied sciences (agronomy, animal husbandry, fisheries, forestry, horticulture, other allied subjects)
- 4.2 Veterinary medicine

5. SOCIAL SCIENCES

- 5.1 Psychology
- 5.2 Economics
- 5.3 Educational sciences (education and training and other allied subjects)
- 5.4 Other social sciences [anthropology (social and cultural) and ethnology, demography, geography (human, economic and social), town and country planning, management, law, linguistics, political sciences, sociology, organisation and methods, miscellaneous social sciences and interdisciplinary, methodological and historical SIT activities relating to subjects in this group. Physical anthropology, physical geography and psychophysiology should normally be classified with the natural sciences].

6. HUMANITIES

- 6.1 History (history, prehistory and history, together with auxiliary historical disciplines such as archaeology, numismatics, palaeography, genealogy, etc.)
- 6.2 Languages and literature (ancient and modern)
- 6.3 Other humanities [philosophy (including the history of science and technology) arts, history of art, art criticism, painting, sculpture, musicology, dramatic art excluding artistic "research" of any kind, religion, theology, other fields and subjects pertaining to the humanities, methodological, historical and other SIT activities relating to the subjects in this group]