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## **D16.1 Dissemination Strategy Plan**

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## Health-e-Child Consortium

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- 03 I.R.C.C.S. Giannina Gaslini (IGG)
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- 05 Assistance Publique Hopitaux de Paris – Necker (APHP)
- 06 European Organisation for Nuclear Research (CERN)
- 09 University of the West of England (UWE)
- 10 University of Athens (UoA)
- 11 Università degli Studi di Genova (DISI)
- 12 The French National Institute for Research on Computer Science and Control (INRIA)
- 13 European Genetics Foundation (EGF)
- 14 Aktsiaselts ASPER BIOTECH (Asper)
- 15 Gerolamo Gaslini Foundation (FGG)
- 16 Maat G Knowledge (MAAT)

## Table of Contents

<b>EXECUTIVE SUMMARY .....</b>	<b>5</b>
<b>1. DISSEMINATION STRATEGY .....</b>	<b>6</b>
1.1 The Health-e-Child Project.....	6
1.2 The Health-e-Child Message.....	7
1.3 HeC and Personalised Health Care .....	8
1.4 Identification of Target Groups and End Users.....	9
<b>2. DISSEMINATION CHANNELS .....</b>	<b>11</b>
Conferences and clustering/networking events .....	11
2.1 Health-e-Child and EGEE.....	12
2.2 Other dissemination channels .....	12
2.3 Broader public awareness: The Genoa Festival of Science .....	12
2.4 HeC Final Conference .....	13
<b>3. EXPLOITATION PLAN/ACTIVITIES .....</b>	<b>15</b>
3.1 CO01 Siemens .....	15
3.2 P10 University of Athens .....	16
3.3 P12 INRIA.....	16
3.4 P14 ASPER.....	17
3.5 P06 CERN .....	17
<b>4. DISSEMINATION INSTRUMENTS .....</b>	<b>18</b>
4.1. Project Logo.....	18
4.2 Communication templates.....	18
4.3 Public Website .....	19
4.4 Newsletter.....	25
4.5 Project brochure, posters and bookmarks .....	25
4.6 Exhibit Booths .....	26



<b>4.7 Relevant publications .....</b>	<b>26</b>
<b>4.8 International scientific journals List.....</b>	<b>26</b>
<b>4.9 Training Courses .....</b>	<b>28</b>
<b>CONCLUSIONS.....</b>	<b>29</b>

## Executive Summary

This document outlines the elements that define the strategy to disseminate the actions and results of Health-e-Child (HeC). This deliverable has been drawn up according to an 18-month plan which will be updated yearly as the project evolves. In this sense the tasks indicated cannot be considered as exhaustive nor set in stone, and additional activities may be added to the scope of activities undertaken to appropriately disseminate HeC.

The guidelines for HeC dissemination are based on the following principles:

- conception of dissemination as “knowledge sharing” on a bi-directional level;
- cross fertilisation and liaison with industrial, research, and standardisation communities;
- involvement of external organisations and experts in HeC;
- involvement of independent experts to validate HeC protocols and entry criteria;
- transfer of results to the industrial, research, and standardisation communities;
- establishment of close collaboration with related projects;
- publication of HeC results in relevant international scientific journals;
- organisation of seminars and workshops within relevant conferences in the area, producing ad hoc brochures and posters;
- set-up of a web site dedicated to the project, containing a public area for general communication and a restricted area for exchange and knowledge sharing amongst consortium members;
- publication and circulation to interested communities and stakeholders of a quarterly newsletter.

Health-e-Child seeks to develop a strong brand image, recognised by both the information technology and biomedical/paediatrics communities, in order to become a quality label and a benchmarking reference for the application of advanced technology in biomedical informatics.

The HeC Consortium is well aware that the nature of the project and its evolution may well dictate changes in the course and enactment of some of the activities set out below. In fact, numerous dissemination channels not foreseen here may come into being and may demand exploitation, while some activities deemed promising at present may in the future be found to be unattractive and/or ineffective. Health-e-Child will nonetheless adhere to the above mentioned overriding principles in its further pursuit of the broadest array of dissemination activities possible.

## 1. Dissemination Strategy

### 1.1 The Health-e-Child Project

The original HeC project proposal featured a *future HeC scenario* describing the case of a child born to a family in which there had been an occurrence of idiopathic dilated cardiomyopathy (DCM). This case study fittingly exemplified the clinical application of the results the project would endeavour to achieve.

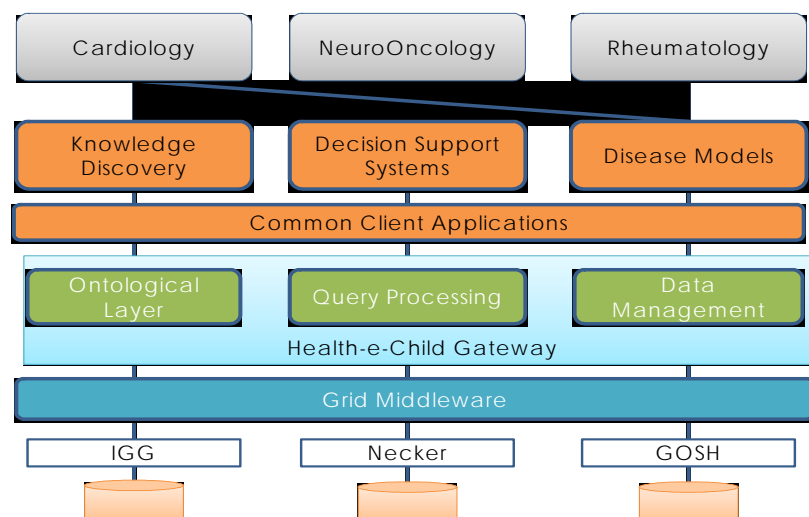
Fashioned around three paediatric diseases with at least partly unknown causes, classification and/or treatment outcomes - heart diseases (right ventricular overload [RVO], cardiomyopathies), inflammatory diseases (juvenile idiopathic arthritis [JIA]), and brain tumours (gliomas) - the HeC system is working to establish the means and tools for multi-site, vertical, and longitudinal integration of biomedical data, information and knowledge delivered via a Grid-based platform, supported by robust tools for search, optimisation and matching processes.

Indeed, the project brings together three different user communities, in a well balanced configuration, which roughly can be described as *three thirds*: one third is made of clinicians and health care providers from paediatric cardiology, rheumatology and neuro-oncology departments, bringing the indispensable expertise to identify relevant clinical research directions; the second third is represented by medical imaging and health IT experts who bridge the clinical and IT worlds; finally, the last third is made up of grid and distributed computing experts able to harness the power of the grid to solve requests coming from the above mentioned communities. This mixture of expertises is what enriches and distinguishes HeC.

The core of HeC revolves around its efforts dedicated to meeting the challenges entailed in biomedical information analysis. Central to these are the project's research activities centring on the tasks aimed at building the enabling tools and services that will improve the quality of health care and reduce its cost by increasing efficiency through:

- Integrated disease models
- Cross modality information fusion and data mining for knowledge discovery
- Database-guided diagnostic and treatment decision support systems for the advancement of personalised medicine.

Health-e-Child at a glimpse



## 1.2 The Health-e-Child Message

The future scenario case study, and its replica for the two other medical domains tackled by the project (paediatric rheumatology and brain tumours), represents the cornerstone of the dissemination strategy which the HeC Consortium plans to enact in order to illustrate to all potential stakeholders how the HeC system will strive to become a pivotal pole of attraction for clinical developments in paediatrics.

The outlook within the EU envisages a rapidly evolving healthcare scenario, where pharmacogenetics know-how is expected to become the broad common standard, translating individual metabolic fingerprints into personalised medicine tailored to individual needs, supported by distributed medical teams and ongoing multidisciplinary biomedical research. The former EU Health Commissioner David Byrne was often quoted as saying that “health is wealth”: a report on *The contribution of health to the economy in the European Union*, published in 2005 by the Directorate-General for Health and Consumer Protection of the European Commission<sup>1</sup>, indicated that preventing ill-health is more cost-effective than treating it, and that care rather than cure has to be the watchword. Four specific concerns relevant to paediatrics were singled out:

- good health in childhood enhances cognitive functions and reduces school absenteeism and early drop-out rates;
- children with better health can be expected to attain higher educational levels and therefore be more productive in the future;
- policy-makers who are interested in improving economic outcomes have a strong case for considering investment in children health as one of the options by which to meet their economic objectives;
- most of the EU Member States are far behind the United States where research can be undertaken with the benefit of a number of public domain longitudinal surveys.

These concerns are also key to the vision underpinning HeC, and will receive strong emphasis in HeC dissemination efforts. Indeed, the message that HeC intends to spread and around which it will base its dissemination activities and actions, both within the IT and biomedical/paediatric communities, to other major stakeholders (e.g., public health authorities) and to the general public, is the assumption that existing healthcare processes and models will likely be unable - over the next decade - to cope with increasing demographic changes and increasing demand in expectations, unless coordinated European public policies begin to more effectively implement innovative e-Health solutions, such as that pursued by HeC.

In this context, HeC endeavours to be recognised as an indispensable tool for paediatrics in daily clinical practice, decision making, and research: a tool accessible at any time and from anywhere, offering a user-friendly, multi-modal, efficient, and effective interaction and exploration environment. Ultimately, with the HeC system, information should have no conceptual, logical, physical, temporal, or personal borders or barriers, but should be available to all professional caregivers with the appropriate level of clearance.

The overriding vision is for the HeC system to become the universal biomedical knowledge repository and communication conduit for the future, a common vehicle by which all practitioners will access, analyze, evaluate, enhance, and exchange and use biomedical information of all forms.

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<sup>1</sup> M. Suhrcke, M. McKee, R. Sauto Arce, S. Tsovala, J. Mortensen, *The contribution of health to the economy in the European Union*, 23 August 2005.

The HeC consortium is aware that the true strength of the project will arise from amassing large amounts of data and building relations and correlations from existing data. This is why HeC places particular importance on building bridges with other projects. The importance of involving an increasingly wider user base was mentioned above, and discussions on collaboration with other projects and initiatives outside HeC are continuously ongoing, especially through the efforts of the HeC Clinical Coordinator, to explore how and under what conditions other healthcare centres could join the existing clinical HeC partners in order to stimulate inputs and to provide outputs that could broaden the number of enrolled patients. HeC is well aware that the involvement of additional health care centres must come about according to established and recognized regulations and principles, and as such will progressively seek to enlist the expert advice of independent advisors who will be able to validate HeC protocols and entry criteria.

The dissemination activities planned in the HeC project aim to foster productive exchange among a large and varied group of stakeholders. Dissemination is therefore seen as an exercise in “knowledge sharing”. Efforts will be bi-directional, inasmuch as while the HeC project will disseminate its results, it will likewise simultaneously attempt to recruit external organisations and actors to share their expertise. It is hoped that a variety of select external actors and users will become involved in the initiative, thereby expanding and enhancing the base of data and knowledge in the community. Indeed, such “active dissemination” among clinical centres promises to generate a valuable contribution for the project, since the more health care providers can be involved, the more patient data can be accumulated. Already after 18 months, negotiations to include leading clinical centres - the Bambino Gesù Children’s Hospital of Rome (IT) and the Department of Paediatric Cardiology of Johns Hopkins University (Baltimore, MD, USA), are being finalised.

Knowledge sharing is also currently carried out within the Consortium itself. With such a large group of professionals coming from so many different research domains the first objective of the knowledge sharing exercise is convergence: building consensus is an integral component of knowledge sharing. To achieve this objective, a series of thematic workshops have regularly been held with the objective of transferring a level of knowledge about the various domains necessary for stakeholders to effectively benefit from the collaboration. Key to the successful implementation of this activity is the HeC Technical Coordinator, Martin Huber, and the HeC Clinical Coordinator, Giacomo Pongiglione.

### **1.3 HeC and Personalised Health Care**

Many of the applications that HeC is developing fit appropriately with the movement in the health care industry towards personalized medicine. It is the Consortium’s hope to highlight these in all forthcoming dissemination activities and to position HeC within this industrial revolution, providing a foretaste of what will be the care systems of the future. For example, the pan-European interoperability is one of the fundamental components of HeC through its GRID platform, and having dealt with many of the legislative and regulatory issues involved with the transfer of medical information across national borders, the Consortium believes that it has acquired some “know how” that might be of benefit also to other European projects. Based on clinical ownership, and not patient ownership, HeC is creating an anonymised online medical record system for all of the patients enrolled in the program which can be accessed and edited across various EU member states. The functions and capabilities of these anonymised records are likely partially to anticipate those which any European Electronic Health Record System would need. At another level, the concept of the e-child, which is a core element of HeC, anticipates some of the descriptive, integrative and predictive goals implied by the new attention brought by FP7 to patient-specific computer models for personalised and predictive healthcare and ICTbased tools for modelling and simulation of human physiology

and disease-related processes, where patient-specific computational modelling of organs and diseases, data integration combining also genetic data with biomedical imaging, new knowledge extraction through innovative software tools for data mining, representation, formalisation and image processing able to integrate heterogeneous information from distributed databases, are the basis for developing the Virtual Physiological Human methodological and technological framework for enabling the investigation of the human body as a single complex system

#### 1.4 Identification of Target Groups and End Users

Achieving the mission and ambitions summarized above requires a consolidated effort aimed at establishing links with distinct - but overlapping - target groups and end users: **IT specialists, paediatric health care providers, and health care authorities and policy makers**. Reaching each of these user bases involves varying approaches, but for purposes of simplification, these can be defined as either clustering activities with other ongoing actions/projects sharing similar or complementary goals, or through conference activity, be this at periodic venues or specific HeC-organized and sponsored events.

Regarding the former, the project is in the position to exploit numerous opportunities: many HeC Consortium members are partners in more than one ongoing EU-funded project/network sharing overlapping missions with which HeC plans to liaise and establish and/or enhance relations. Particularly telling is the close collaboration with the **Enabling Grids for E-Science** project and HeC's utilisation of the EGEE's grid middleware "gLite". Other conspicuous examples of projects sharing partners with HeC are **HealthGrid** and **SHARE**, two other EU-sponsored actions with which HeC shared exhibition space at the EGEE '07 Conference held in Budapest in October 2007. The three projects will continue to collaborate in this fashion in order to nurture enhanced cooperation across domains, as well as to defray costs entailed in the rental of exhibition space.

In addition to EGEE, HealthGrid and SHARE, other projects sharing a common denominator (e.g., grid technologies, e-health applications) and with which closer ties will be sought:

PONT (Parallel Optimisation of New Technologies for Post-Genomics Drug Discovery)

ETUMOUR (Web Accessible MR Decision Support System for Brain Tumour Diagnosis and Prognosis, Incorporating In Vivo and Ex Vivo Genomic and Metabolomic Data)

MULTIMOD (Simulation of Multiple Medical-Imaging Modalities: A New Paradigm For Virtual Representation of Musculo-Skeletal Structures)

GRASP (Grid Application Service Provision)

@NEURIST, Integrated Biomedical Informatics for the Management of Cerebral Aneurysms

ACGT, Advancing Clinico-Genomic Clinical Trials on Cancer

COCOON, Building knowledge driven and dynamically networked communities within European healthcare systems

HEALTHAGENTS, Agent-based Distributed Decision Support System for Brain Tumour Diagnosis and Prognosis

SAPHIRE, Intelligent Healthcare Monitoring based on Semantic Interoperability Platform

EuResist, Integration of viral genomics with clinical data to predict response to anti-HIV treatment

This list will clearly expand as other initiatives come into existence.

Moreover, HeC will seek out other transversal initiatives, such as BELIEF (Bringing Europe's eLEctronic Infrastructures to Expanding Frontiers) and EELA (E-infrastructure shared between Europe and Latin America), two EU 6th Framework Programme funded projects whose aim are to promote European e-infrastructures in other parts of the world as well as to diverse communities. Indeed, these two actions share with HeC the message and vision that e-infrastructures constitute an answer to several of the most complex challenges presented by the worlds of biology and medicine (the processing of huge numbers of cases, experimental results, the integration of data), as well as to create an exchange for ways to chart the incorporation of e-infrastructures and grid technologies in the mainstream of biomedical research.

In addition, bearing in mind the project's overriding vision and its goal to develop and deploy tools that promote the uptake of e-health and personalised medicine applications, the HeC Consortium will progressively make every effort to involve other major stakeholders and end users, namely public health decision-makers and authorities. A first attempt in this direction will be offered by the project's planned presence at the 2007 Genoa Festival of Science.

## 2. Dissemination channels

### Conferences and clustering/networking events

For the HeC Consortium, raising awareness about the project and the results it achieves is not only a contractual duty and deliverable; rather, it is an opportunity to spread the vision that the Consortium is striving to make a reality. Pivotal in this regard are the efforts made to embrace every occasion possible - be it by individual partners or through joint appearances by more than one Consortium Member - to make Health-e-Child's presence felt, to both specialized and lay audiences.

Pivotal to the increased visibility of HeC is its proactive presence at regional, national and international events and gatherings focusing on the information technology and biomedical domains tackled by the project, and more generally, on the development of e-health scenarios, applications and solutions.

Participation at events that are deemed germane to the objectives and mission of HeC take one of two forms, namely by representatives of HeC partners to present ongoing work and outcomes achieved thanks to the project, or as a formal, concerted Consortium-sponsored presence with the rental of display space for the diffusion of project dissemination materials. In many instances, it is quite likely that the project is represented at both levels.

During the first 18 months of the project, it became increasingly apparent that participation at such events - be it by individual HeC partner organizations or as a concerted attendance - would be dictated by the both the scope of the event itself and the development stage of the project. With this in mind, the Consortium has agreed that the following conferences focusing either on Grid technologies or on the subject of e-health, and each held on an annual basis, are venues where the HeC must make every attempt to be proactively present in order to illustrate its goals and results:

- Conferences and User Forum Events organised by the Enabling Grids for E-science project;
- Conferences organised by the HealthGrid project (next scheduled meeting: Chicago 2-4/06/2008)
- The World of Health IT conference and exhibition series (from 2008 onwards; dates and venue of next event to be announced)
- In addition, the diversity of technological and clinical/medical disciplines on which the project focuses provide a wide array of venues at which specific project activities and results can be appropriately presented. These include:
- The conference series of the International Society for Medical Image Computing and Computer-assisted Intervention (MICCAI) (next scheduled meeting: New York, 4-4/09/2008)
- The Information Processing in Medical Imaging conference series (meetings held every 2 years; next scheduled event in 2009)
- The Data Integration in the Life Sciences workshop series (dates and venue of next event in 2008 to be announced)
- The series of International Symposium on Computer-Based Medical Systems (CBMS) organized by the Institute of Electrical and Electronics Engineers (IEEE) (next scheduled meeting: 17-19/06/2008, University of Jyväskylä, Finland)

- Events organised by the Statistical and Applied Mathematical Sciences Institute (SAMSI)
- The Computer Assisted Radiology and Surgery (CARS) conference series (next conference scheduled for June, 2008, Barcelona)
- European Conference on Computer Vision (ECCV) (next scheduled meeting 12-18/10/2008, Marseille)
- Annual conferences and venues at which HeC will attempt to make its presence felt through the presentation of posters and invited talks include: the European Association of Paediatric Cardiology, the European Society of Paediatric Neurology, the European Society of Paediatric Radiology, the European Society of Paediatric Rheumatology, the European Society of Human Genetics.

## 2.1 Health-e-Child and EGEE

As a major project within the European eHealth and IT research communities Health-e-Child was very visible in the EGEE community in 2007. HeC had its own booth at the Open Grid Forum 2007/EGEE Users Forum in Manchester in April. This booth was used to disseminate news of the project in general and to present the demonstration which was submitted to the EC review in March to the wider research community. In October Health-e-Child teamed up with two other health related EGEE project, HealthGrid and BioMed, for a joint booth at the EGEE conference in Budapest. The economies of scale that were achieved with this cooperation have made it the template for future conference participation. Along side the expanded booth in Budapest an updated demonstration of the Health-e-Child platform was submitted along with 50 other demonstration to the EGEE07 evaluation committee. Health-e-Child was ranked in the top five and achieved a runners-up award. The projects dissemination activities will be broadened in the following years to further strengthen the Health-e-Child brand name and exposure within the related research communities.

## 2.2 Other dissemination channels

In addition, the success of HeC dissemination will rely heavily on the efforts of single partners in exploiting occasions and opportunities - be they at the local, national or international level – to generate exposure of the project. Activities in this regard range from the simple provision of links from institutional web sites to the project's portal, to postings featuring HeC on partner's institutional web sites, to seminars/workshops showcasing the project, to articles in institutional newsletters and publications.

Moreover, the Consortium will strive to retain its presence in the periodic publications of the European Commission, chief of which are the CORDIS website for research and development (and related monthly publications) and the recently launched e-Health Newsletter ([http://ec.europa.eu/information\\_society/activities/health/newsletter/index\\_en.htm](http://ec.europa.eu/information_society/activities/health/newsletter/index_en.htm))

## 2.3 Broader public awareness: The Genoa Festival of Science

A telling example of the HeC Consortium's attempts to reach a broader general public is its inclusion in the 2007 Genoa Festival of Science. Organized for the past four years and arguably one of the most popular and well-attended "science communication events" in Europe - with over 250,000 visits at 90 venues throughout the city - the 13-day Genoa festival brings together world renown experts (including Nobel laureates) in fields ranging from

astrophysics to biological/medical sciences, from mathematics to nanotechnologies, in a multifaceted programme of exhibits, conferences and laboratories aimed at promoting greater public awareness and understanding of science and technology.

With its overriding vision of personalised medicine afforded by scientific and technological breakthroughs, HeC proposes a ½-day forum to showcase the project as an anticipation of the structural problems that all healthcare systems will face in trying to adjust to future demographic changes, explaining the rationale of its ambition for becoming the universal paediatric knowledge repository and communication conduit for future policy makers.

The Genoa festival is seen as a perfect opportunity to achieve broader public dissemination. Within this broad context, a session is dedicated to healthcare advances and to the new vision of personalised medicine afforded by scientific and technological breakthroughs such as those being developed by HeC in the area of vertical data integration, knowledge discovery and decision support systems. The HeC session shall move from analyzing the assumption that existing health care processes and models will unlikely be able, over the next decade, to cope with increasing demographic change, current demand crises and growth in expectations, unless coordinated European public policies begin to much more effectively pursue innovative e-Health solutions. The idea is to showcase HeC as an anticipation of similar scenarios, explaining the rationale of its ambition of becoming the universal paediatric knowledge repository and communication conduit for the future policy makers. The program of HeC will be explained, showing its goals of:

- collecting all clinical data of child patients into vertically integrated databases,
- reading and interpreting the data through new IT systems driven by the Grid system of distributed computing,
- and connecting leading European paediatric hospitals, gradually widening the system to include a growing number of European paediatric centres, creating a next generation diagnostic system while at the same time providing researchers with an essential tool to encourage new discoveries.

What will also be explained is how the ambition of HeC to provide a foretaste of the health care systems of the future is based on:

the endeavour to gradually involve other paediatric hospitals, thereby widening its scope to other diseases (beyond the initial ones of cardiology, oncology and rheumatology), and to make the HeC platform - built on knowledge developed by clinical centres of excellence - a tool for European paediatricians to access a system to aid diagnoses;

the effort to minimise, this way, the risk of diagnostic errors, while allowing medicine to take an important step towards a greater intertwining of information technology with scientific research.

The experience gained from HeC's involvement in this event will be germane to the actions undertaken to raise awareness in the general public in the years to follow (2007 – 2009).

## 2.4 HeC Final Conference

Actions addressed to the general public will culminate in 2009 with the international conference on the outcomes and future directions of HeC organized by the FGG in Genoa. Plans for this event will be finalized only by the 4th quarter of 2007. The HeC International Conference will be organized at the project's conclusion in cooperation with all its current and recruited stakeholders. Dedicated to the scientific and technological - not to mention societal - results of HeC, the conference will strive to raise the awareness of the biomedical community and of the related industry, as well as of a significant segment of the broader non-scientific



audience interested in advances in paediatrics, in the project's accomplishments and future developments.

Pivotal to addressing and involving the broader paediatric community will be the actions of HeC partner FGG. The FGG and HeC Dissemination WP Leader Lynkeus will build on the experience they have already consolidated in this area through their joint organisation of the international conference "Children & the Mediterranean" (Genoa, January 7-9 2004), attended by over 900 participants and featuring numerous eminent scholars and illustrious guest speakers including former President of the European Commission, Romano Prodi, the President of the International Paediatric Association, Jane Schaller, and 1996 Nobel Laureate in Medicine, Rolf M. Zinkernagel.

### 3. Exploitation Plan/Activities

#### 3.1 CO01 Siemens

##### *Disclaimer*

HeC does not develop any products. The prototypes generated during the course of HeC are not to be used for clinical routine. Systems developed in parallel or after the HeC project will of course follow strictly the European Medical Device Directive and will undergo all necessary tests, e.g., CE labeling, FDA approval, etc.

Siemens has huge experience in medical in-vivo and in-vitro field and in clinical IT systems. Therefore Siemens will exploit its results from HeC in the following directions.

##### *Applications*

During the duration of HeC Siemens is mainly involved in the areas of decision support systems based in knowledge discovery. Furthermore Siemens interest lie in the modeling aspects for the data, its visualization, and primarily its integration. One important new visualization technique is tree map. Here we provide a new integrate view on huge data sets with many different data sources.

In small HeC demonstrates the in-vivo and in-vitro integration of data, i.e. integration of laboratory, omics data with the traditional imaging examinations. This integration leads to a holistic approach for clinical decision support systems leading to a new personalized health-care. A first application in that direction is the "Case-Reasoner" where similar data sets based on a pre-selected feature ranking are returned.

Another area are the tools that are enhanced within HeC. Here especially the data extraction tools for distributed data collection are used at the moment. These tools will be developed further to serve better the needs of research trials as well as the requirements of the clinical partners.

##### *Regulations*

The work package dealing with the collection and distribution of data across hospital boundaries and country borders will generate important knowledge about how to deal with the European laws and regulations. This knowledge will provide in-depth guidance for all partners for distributed data collection and distribution.

##### *Ontologies*

The description and modeling of our clinical data and medical knowledge is done with ontologies. Here the important research results of the diseases, i.e., pediatric rheumatology, brain tumors, and JIA are captured. This allows us to later use this knowledge to be used in clinical applications like cDSS and KD.

##### *Data*

The data collection and its annotation are important inputs for the development and testing of new algorithms in the areas of knowledge discovery and clinical decision support systems. Those integrated data sets can further be used to verify and fine-tune the prototypes developed during the HeC project. Therefore clinical data is an important asset of the project.

##### *Visibility*

Siemens as the leading health-care provider increases its visibility in the pediatric sector and community while doing research in this area. Here new technologies from data integration towards clinical decision support systems are applied to children's personalized medicine.

We plan to connect approximately 25 hospitals to the HeC biomedical platform over the next years. First steps towards this goal are the negotiations with JHU hospital in Baltimore, U.S.A. and OBPG hospital in Rome, Italy.

### 3.2 P10 University of Athens

National and Kapodistrian University of Athens as a high level public educational institution has two aims, to support knowledge and to produce research. The collaboration with other institutions, organisations and business, and especially the participation in EU funded projects, fosters the achievement of this mission. The results of this participation will be exploited by the University in the following ways:

- New inputs for research will be gained, in our aim to advance the state-of-the-art in biomedical query processing and data mining, and obtain solutions that can be put into practical use.
- Existing infrastructures in the UoA can be assessed and improved in the context of international know-how.
- The knowledge transfer regarding e-Infrastructures and the grid can be evaluated. This will open new directions in the educational process and will influence on improvement of this process.
- New schemes to encourage and facilitate collaborative research between academia and industry can be developed and applied.
- New contacts can be made with partners and people from many countries around the world and valuable experiences about the work in such projects and the state of the art in e-Infrastructures, ontologies, biomedical query processing, decision support systems, and mining of complex integrated data can be gained. Moreover, further collaboration with these people can be developed and sustained, even after the closing of the project.

### 3.3 P12 INRIA

INRIA will study with the Health-e-Child partners the possibility to license all the elements of its technology that can support the exploitation of the results obtained within the Health-e-Child consortium. In particular, this may concern the geometric models of the heart and the brain, along with the registration tools relating generic anatomies (atlases) to patient-specific images and data or images in longitudinal studies. A second set of methods that could potentially be transferred is related to the modelling of the physiology, for instance models of evolving tumours and electro-mechanical models of the heart contraction. INRIA will also investigate the possibility to exploit the models developed in the paediatric domain in other medical domains (e.g. general cardiology or neurology) or in other disciplines, e.g. in neuroscience. The knowledge created through the Health-e-Child project will also be used to improve the models and potentially impact clinical practice in the long term by making some of the models and imaging tools accessible to clinical research.

### 3.4 P14 ASPER

The exploitable result of the work done in Asper in co-operation with EGF, IGG, Siemens and in case of need other partners will be DNA testing microarray for detection of mutations that are connected to (paediatric) pilocytic gliomas. The contribution by partners will be to compile a scientifically relevant mutation list to ensure the commercial success of this test. The test will be ready for the second quarter of 2009.

### 3.5 P06 CERN

Exploitable Knowledge:

-Expertise in EGEE gLite deployment, support, operation and management.

#### Exploitable product(s) or measure(s):

-Indirectly: EGEE gLite software stack; monitoring and operations tools; user support tools

#### Sector(s) of application

-Any application that requires a controlled environment to manage distributed compute and storage resources of virtual organization(s).

#### Patents:

-Indirectly: The EGEE software license can be found here: <http://egee-jra2.web.cern.ch/egee-jra2/license.html> .

#### Owners & Other partners:

-Indirectly: for what concerns ownership, refer to the EGEE software license <http://egee-jra2.web.cern.ch/egee-jra2/license.html> .

## 4. DISSEMINATION INSTRUMENTS

### 4.1. Project Logo

A wide set of logos were produced at month 1 immediately after the Kick-off meeting.

A final logo was chosen through voting by all partners as the one to be used officially.

The logo chosen shows the image of a child being held by containing elements representing the personalisation and innovation of medical systems.



Figure 1 HEC logo

### 4.2 Communication templates

Most of the communication templates depended on the decision on the final logo. After voting by all partners, a common design of the consortium communication protocols (i.e. .ppt, .doc, etc.) was developed. Here below are examples of latest ppt template and business cards.



Figure 2 HEC .ppt template



**Figure 3 HeC business card**

### 4.3 Public Website

HeC's Internet presence was achieved through a new website created specifically for this purpose (<http://www.health-e-child.org/>) Indeed, convinced of the importance of the tool as a means for dissemination, a first release of the HeC portal was launched in March 2006, well in advance of forecasted implementation, since the project's DoW foresaw its completion by project month 18. The portal was redesigned with an improved look and feel in October 2006, implementing the Plone-Zope technology platform, whereby single partners can independently upload documentation, images, etc., thereby remotely populating the web site with content.


**Figure 4 The Health-e-Child Project website Home Page**

The HeC portal will be used as the main dissemination tool, covering the project's goals, objectives, accomplishments, background information and partner's role and contribution. It will thus have to run parallel with the project's evolution in order to provide timely and appropriate information, thereby requiring constant updating and maintenance.

Project partners will be asked to take a leading role in promoting public exposure and awareness of the project by providing links through their institutional web sites to the HeC portal, and by posting presentations showcasing the project on their web sites.

Additionally, HeC partners will be the main sources of content that will progressively populate the portal. Supervision of this activity will be entrusted to the HeC Technical Coordinator.

The Plone/Zope platform has been chosen for its features that facilitate collaborative work among partners and the management of content (CMS). All the actors in the project have received (on request by the leader of each partner) a username and a password to access the website. Within the system, access rights can be managed to separate different working areas.

Main features are: repository of documents, chat functionalities on single pages, templates for content publication, agenda and events modules. The site is backed-up on a regular basis and this has already allowed to restore the site content after misbehaviour or external intrusion.

It must be mentioned that the consortium makes also use of "Project NetBoard", a professional Internet-based collaborative tool for time effective and cost efficient management of projects supported by the European Commission. Project NetBoard comprises groupware modules open under access control, to all partners. This tool will be used for the whole duration of the project and for its archive procedure. The PNB platform is consistent with the use of the website. All the preparatory documents are stored on the website, while Deliverables and other final documents are stored on the PNB platform. Also, PNB allows partners to easily create and update mailing lists, by producing files of grouped email addresses that can be exported in the most common software.

#### *Site Map (Web contents structure)*

The existing contents structure/site map - reflecting the complexity of the interactions occurring within the project - is outlined below.

[About](#)

[Mission](#)

[Description](#)

[Vision](#)

[Impact](#)

[Partners](#)

[Contact](#)

[Events](#)

[Past Events](#)

[Links](#)

[Health-e-Child consortium members](#)

[Newsletters](#)

[HEC Newsletter N. 1](#)

[HEC Newsletter N. 2](#)

[HEC Newsletter N. 3](#)

[Public Documents](#)

[HeC - EC review 2006](#)

[1st Annual European Commission Review](#)

[HeC - Training Courses](#)

[HeC - Public deliverables](#)

[HeC - Dissemination materials](#)

[HeC Documents](#)

[Background Documents](#)



[Contract](#)

[IP Consortium Agreement](#)

[Boards & Committees](#)

[Executive Board](#)

[EB - Meetings and Minutes](#)

[Governing Board](#)

[Project Management Team](#)

[PMT minutes of meetings](#)

[Intellectual Property Rights Committee](#)

[WPs](#)

[WP1](#)

[Public Deliverables](#)

[WP2](#)

[Documents](#)

[Meetings](#)

[Deliverable](#)

[WP3](#)

[WP4](#)

[Meetings](#)

[WP5](#)

[Documents](#)

[Deliverables](#)

[Meetings](#)

[Task Reports](#)

[WP6](#)

[Links](#)

[Papers](#)

[Meetings](#)

[Modeling](#)

[Documents](#)

[Deliverables](#)

[WP7](#)

[Documents](#)

[Meetings](#)

[WP8](#)

[Meetings](#)



[WP8 - GENEVA MEETING NOTES \(11/06\)](#)

[WP9](#)

[brain tumours](#)

[rheumatology](#)

[cardiology](#)

[meeting notes](#)

[Cardiology Protocols](#)

[WP10](#)

[WP11](#)

[WP11 meeting in Sophia, Feb 6 2006](#)

[Input / Output folder](#)

[WP12](#)

[Documents](#)

[Deliverables](#)

[Meetings](#)

[WP13](#)

[Meetings](#)

[References](#)

[WP14](#)

[Documents](#)

[Meetings](#)

[Task Reports](#)

[WP15](#)

[WP16](#)

[Deliverables & Milestones](#)

[D1.1 Self Assessment Plan](#)

[D1.1 Quality Assurance Guidelines](#)

[D.1.2a First Quarterly Report](#)

[D1.2b Second Quarterly report -Draft](#)

[D2.1 Users Requirements Specifications](#)

[WP1 Project Presentation](#)

[Deliverables & Milestones](#)

[D1.1 Assessment Docs](#)

[WP1 Project Presentation](#)

[State of the art report A6 \(D11.1, D12.1, D13.1\)](#)

[versions](#)



[drafts](#)

[templates](#)

[subchapters for version 01](#)

[D 16.1 Dissemination Strategy Plan](#)

[D 9.1 Report on diagnostic coding system and data collection protocols](#)

[D 1.2.b Quarterly Report](#)

[D 1.4 Project Presentation](#)

[D 3.1 Informed consent](#)

[D1.2c Quarterly Report n. 3](#)

[DoW II](#)

[WP1 contributions](#)

[WP3 contributions](#)

[WP4 contributions](#)

[WP5 contributions](#)

[WP6 contributions](#)

[WP7 contributions](#)

[WP8 contributions](#)

[WP9 contributions](#)

[WP10 contributions](#)

[WP11 contributions](#)

[WP12 contributions](#)

[WP13 contributions](#)

[WP14 contributions](#)

[WP15 contributions](#)

[WP16 contributions](#)

[Brain Tumour Genetic Study](#)

[DoW II Drafts and Versions](#)

[A6 drafts](#)

[Presentations and Documents due for public dissemination](#)

[D1.3 Annual report](#)

[Management report](#)

[Activity report](#)

[Separate files Exec Summary and Dissemination Plan](#)

[D 3.2 Annual Report on Ethical and Legal issues](#)

[D1.2e Quarterly Report](#)

[Workshops & Meetings](#)



[2006 Workshops & Meetings](#)

[Erlangen Kick-off Meeting 12-13/1/2006](#)

[Executive Board meeting 06/02/2006](#)

[WP11 meeting at INRIA 06/02/2006](#)

[Meeting with Project officer 08/02/2006](#)

[Meetings at CERN 18th-24th March 2006](#)

[Brain tumour meeting Gaslini 20 April 2006](#)

[Meeting with Gaslini 16 May 2006](#)

[H-e-C Workshop at CERN 30/05-02/06/2006](#)

[UCL / GOSH - 20 June 06](#)

[PMT & GB & Internal Audit Meeting Munich 11-12 July 2006](#)

[Toledo 23-26 Oct 2006](#)

[Athens - PMT meeting 11 Dec 06](#)

[Athens - A4 meeting 12-13 Dec 2006](#)

[2007 Workshops & Meetings](#)

[Paris Meeting 15-18 January 2007](#)

[EC Review March 2007](#)

[PMT Meeting at APHP - May 15, 07](#)

[Events](#)

[HeC News](#)

[Admin & M-Lists](#)

[Project Netboard Platform](#)

[1st Annual European Commission Review](#)

[Day 1 - 6th March 2007](#)


[Day 2 - 7th March 2007](#)

[Feedback from the European Commission](#)

[News](#)

[News](#)

 [HeC at the Genoa Festival of Science 13-06-2007](#)

 [HeC at OGF 20, 7-11 May '07 23-05-2007](#)


 [HeC - 1st Training Course Abstracts 12-04-2007](#)

[More news...](#)

[Upcoming Events](#)

 [IEEE EMBC 2007 Lyon, France, 23-08-2007](#)

 [EGEE '07 Budapest, 01-10-2007](#)

 [The World of Health IT 2007 Conference & Exhibition Vienna, 22-10-2007](#)

 [CeHR: International Conference 2007 Regensburg, Germany, 02-12-2007](#)

[Previous events...](#)

[Upcoming events...](#)

### *Mailing lists*

To increase the project's exposure as much as possible amongst potentially interested users, specific mailing lists reflecting the research domains tackled by HeC will be created.

All HeC partners and stakeholders (including the Commission) will be invited to submit the e-mail addresses of individuals and/or organisations who might be interested, thereby targeting the existence of the newsletter while respecting constraints on unsolicited email.

Nevertheless, the website will also contain a subscription module for interested readers.

### **4.4 Newsletter**

A quarterly Newsletter will be published beginning with the last quarter of 2006. It will be accessed through the public area of the HeC portal, and its mission will be to inform about the main results of the project as it evolves, partner profiles, case study scenarios, and pertinent major events. It will also contain, however, interesting news concerning background research in similar areas, in order to raise its appeal among potential readers.

The HeC newsletter will also be made available for e-mail distribution for interested parties. The newsletter will be issued quarterly (March, June, September, December of each year), exclusively by e-mail. It will be possible to subscribe to it on the website, but every effort will also have to be made to contact any potentially interested in receiving it. All HeC partners and stakeholders (including the Commission) will be invited to submit the e-mail addresses of individuals and/or organisations who might be interested, thereby targeting the existence of the newsletter while respecting constraints on unsolicited email. One example of a way to advertise the existence of the newsletter will be to have it referred to on the CORDIS website, and to ensure that it is referred to in the CORDIS newsletter.

### **4.5 Project brochure, posters and bookmarks**

A HeC brochure was prepared by the Project Coordinator, and this text will be the basis for a published brochure to be disseminated at conferences and workshops relevant to HeC. It shall be a useful tool for disseminating basic information on HeC and its objectives to various target groups.

Posters will be produced to illustrate the objectives of the project. They will be distributed to the partners in order to be publicised within partner institutions and will be displayed at the events, e.g. conferences, workshops, where the project is featured.

An HeC bookmark, summarising the goals, partnership and graphics of the project in a limited 2x5 cm format, will be printed for distribution at conference events and through individual contacts by Consortium partners.

#### 4.6 Exhibit Booths

As alluded above in section 2.4.3 on the identification conferences and venues at which HeC would seek to guarantee its attendance in a concerted, Consortium-sponsored manner, the project will carry through with plans to set up a dedicated HeC booth for exhibition purposes at numerous major conferences dealing with HeC-related subject matter. Because of inherent costs for the rental of exhibition space and booth shell, as well as the staffing of the booth for the duration of an event, funding resources permitting, the set up of an HeC booth at 5 or 6 select events during the project's lifetime will be evaluated on a case by case basis. In addition, also as mentioned above, HeC will seek to team up with other ongoing projects sharing complementary aims (e.g., SHARE and HealthGrid) in order to defray the inherent costs of exhibition space rental and outfitting.

As an indication, and judging from experience already gained in the project's first 18 months, conferences focusing either on Grid technologies or on the subject of e-health will provide the venues where the HeC must make every attempt to be proactively present in order to illustrate its goals and results. More specifically, these are represented by

Conferences and User Forum Events organised by the Enabling Grids for E-science project

Conferences organised by the HealthGrid project

The World of Health IT conference and exhibition series

#### 4.7 Relevant publications

Aware that it is a pivotal tool for stimulating knowledge sharing, HeC has already submitted some joint publications in scientific and technical conferences.

- "Health-e-Child: An Integrated Biomedical Platform for Grid-Based Paediatrics", Joerg Freund, Dorin Comaniciu, Yannis Ioannidis, Peiya Liu, Richard McClatchey, Edwin Morley-Fletcher, Xavier Pennec, Giacomo Pongiglione and Xiang Zhou., prepared for the HealthGrid 2006 Conference, Valencia June 2006

- Health-e-Child" booklet for: Resource book of eHealth projects Sixth Research and Development An introduction to the aims and objectives of the HeC project has been published for the ICT/BIOMED conference , Brussels June 2006

This key activity of scientific diffusion will continue to be actively pursued throughout the project's duration, tentatively targeting the journals listed below.

#### 4.8 International scientific journals List

A first list of the most relevant journals to the HeC project was identified early on and will be monitored and continuously updated. The most important ones are shown below:

ACM Trans on Database Systems	American Journal of Human Genetics
Annals Rheumatic Diseases, Arthritis & Rheumatism	Bioinformatics
Circulation	Clinical and Experimental Rheumatology,
Cardiology in the Young	American Journal of Cardiology
European Journal of Human Genetics	European Heart Journal
European Radiology	Human Genetics
Internal Journal of Medical Informatics	IEEE Trans on Knowledge & Data Engineering



IEEE Trans Biomedical Engineering	IEEE Transactions Pattern Analysis & Machine Intelligence
IEEE Transactions Medical Imaging	IEEE trans on information theory
International Journal of Grid Computing	International Journal of Grid Computing & Software Practice & Experience
International Journal of Medical Informatics, Methods of Information in Medicine	International Journal Medical Image Analysis
Neural Computation	Nature
Paediatrics	Neuroimaging
Rheumatology, Software Practice & Experience	Proceedings of the National Academy of Sciences
The Journal of Computational Biology	Studies of Health Technology and Informatics,
The Journal of Medical International Research	The Journal of Healthcare Information Management
The Journal of Machine Learning Research	The Journal of Paediatrics
The Journal of the American College of Cardiology.	The Journal of Rheumatology
	Science

#### 4.9 Training Courses

Dissemination has obvious links to training, and the central objective of WP 15 is to ensure that the project makes state-of the art training available to the project participants and the larger community, which is designed to meet the different individual requirements and training needs. As the clinical applications and tools that HeC endeavours to develop become available, medical professionals must be put in a position to take advantage of them. This is the premise that drives the project's Workpackage 15 on Training, whose central objective is to design and deliver state-of the art training actions, to both the Consortium and the larger biomedical community.

Bringing its 20 plus years of experience in the training and continuing medical education of health care professionals to the project is the European Genetics Foundation (EGF). Key to the successful achievement of EGF's tasks will be their adherence to a tested methodology, whereby

- specific stakeholders' training requirements will be analysed and created;
- a methodology to be followed in order to satisfy the expressed requirements will be detailed;
- training packages for each of the target communities will be designed.

At a secondary - but no less important - level, project-endorsed training activities will surely prove to be an important means of dissemination, attracting the attention of industrial clusters and ideally leading to the involvement of other researchers and research themes that were not envisaged at the outset of the project.

Courses will take on a residential format, but will also be available as webcasts, with lectures available in streaming. All proceedings, including on-demand video of the lectures delivered in streaming - will thereafter be available for downloading from the EGF website.

A first event on "Genetics of Paediatric Inflammatory Diseases" has already been held (April 2007), in collaboration with HeC clinical partner IGG.

Future HeC training courses will be:

"Paediatric Cardiology: From Developmental Models to Clinical Applications", 2008

"Paediatric Brain Tumours", 2009

## Conclusions

As is set out above, HeC will strive to achieve its dissemination goals by adhering to a series of guiding principles:

Conception of dissemination as an exercise of bi-directional “knowledge sharing” and endeavouring to actively liaise with industrial, research, and standardisation communities;

Actively involving external organisations and experts;

Establishing close collaborative ties with projects sharing similar/complementary ambitions and goals;

Publication of project outcomes and results in relevant international scientific journals;

Organization of seminars and workshops as part of conferences sharing the project's subject matter, producing ad hoc brochures and posters;

Maintenance of a dedicated web portal, containing both a public area on which a quarterly newsletter will be published, and a restricted area for use only by the project partners.

Key to the achievement of HeC dissemination goals will be the efforts of single partners in exploiting occasions and opportunities to generate exposure of the project.

Pivotal, as well, will be HeC's constant search for appropriate dissemination channels in addition to or in substitution of what has been outlined above, which will then be documented in the yearly review and updating of this document.