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(draft - July, 25)

Health-e-Child
Integrated Project (IST-2004-027749)

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1. Short Description

This document outlines some preliminary elements for a first draft of an activities strategy for Health-e-Child (HeC), 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, and additional activities may be added to the scope of activities undertaken to appropriately disseminate the actions and results of HeC.

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

- Conceive dissemination as “knowledge sharing” and bi-directional
- Perform cross fertilization and liaison with industrial, research, and standardisation communities
- Involve HeC also external organisations and experts
- Involve independent experts to validate HeC protocols and the entry criteria
- Transfer results to the industrial, research, and standardisation communities
- Establish close collaboration with related projects
- Publish HeC results in relevant international scientific journals
- Organize seminars and workshops within relevant conferences in the area, producing ad hoc brochures and posters.
- Have a web site dedicated to the project, containing both a public area, on which a quarterly newsletter shall soon be published, and a restricted area for use only by the project partners

HeC has the ambition to develop a strong brand image, recognised by both biomedical communities and IT experts, in order to become a quality label and a reference for the application of advanced technology in biomedical informatics.

At the time of drafting of this document, 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.

HeC will nonetheless adhere to the above mentioned overriding principles in its further pursuit of the broadest array of dissemination activities possible. Indeed, the guidelines for HeC dissemination have already allowed in its first six months of existence identifying – and in some instances implementing - those activities and efforts that will ultimately enable the project to achieve its dissemination goals.

2 Dissemination Plan

2.1 “A future Health-e-Child story”

When the HeC project was first submitted to the EC, the proposal featured a *future HeC scenario*, wherein the case of a child born to a family in which there had been an occurrence of idiopathic Dilated Cardiomyopathy (DCM) was presented. Briefly, the story hypothesized that as the child’s biomedical record was progressively collected, all initial data, namely, demographics, familial/pedigree findings, 2D/3D echocardiograms, blood tests (lactate, pyruvate, carnitine, etc. values) and preliminary genetic analyses, would be cohesively integrated into the HeC database. By means of such data integration, all clinical specialists - the paediatrician, the cardiologist, the radiologist and the geneticist - at different sites would be able to share a coherent picture of the child’s health. During the data integration process, the HeC system would apply robust information fusion in order to compensate for uncertain, outlying, and missing biomedical data, and would construct a “generative” model of DCM, building on a collection of past DCM cases, each with biomedical information as inputs and with expert diagnosis or known outcome. The HeC system would also generate a “discriminative” model learned from DCM patients against healthy controls. Advanced computer vision and pattern recognition tools would localise, segment, and characterise the heart chambers automatically from imaging data. An intelligent classification algorithm would then merge the generative and the discriminative models in an optimal way, robustly fusing information collected for the child, and confirming an increased risk of DCM.

The outcome is an integrated disease model for DCM, with clinical, ECG, imaging (ultrasound/MRI), tissue biopsy, and genetic factors acting jointly to contribute to a statistical, geometric, bio- and electromechanical model of the diseased heart. As a “generative” model, it would represent a wide variety of DCM sub-classes in the heterogeneous input space. Since DCM may arise from any one of a variety of pathways, the integrated DCM model would be built upon these complex associations, which would be continuously refined with time. A data acquisition guidance system would thereafter suggest more specific tests, e.g., MRI, catheterisation + biopsy, further gene mutation and chromosomal analysis, SNP analysis, and a personalised monitoring plan. Eventually during monitoring, imaging data would start to show slight left ventricle (LV) enlargement. The doctor would be alerted and would turn to an intelligent retrieval system to search for and examine similar cases from distributed databases. The system would provide easy and intuitive interactions in order to incorporate an expert’s perceptual constraints of similarity (e.g., finding cases with a particular LV shape associated with a certain genotype). The diagnostic decision of DCM onset would thereby be verified and further refined to a DCM subclass.

Finally, the HeC system would also predict disease progression over the years to come. A prevention/treatment plan, such as preventive lifestyles or gene therapy, specifically tailored for the child’s genomic or proteomic profile and existing symptoms would automatically be proffered. The likelihood of a necessary transplant would also be provided in time. Before the scheduled transplant, the system would, on the basis of past patients with similar profiles, warn the attending health care team that this case ran a high risk of rejection (due, e.g., to cytokine gene polymorphism). Therefore, the system would consequently suggest an early follow-up and rejection-prevention plan, which would later be adjusted by post-op biopsy and gene/protein expression profiling.

2.2 Setting up of the project Research Community

This “future story”, and its replica for the two other medical domains tackled by the project (paediatric rheumatology and brain tumours), represents the core 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 pharmacogenetic 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. 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 clinicians will access, analyze, evaluate, enhance, and exchange and use biomedical information of all forms.

2.3 The economic rationale of investing in children’s health and the need of longitudinal surveys

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 Commission¹, 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 key to the vision underlying HeC, and will receive strong emphasis in HeC dissemination efforts addressed to a broader general public.

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

2.4 Knowledge sharing in paediatrics in the European Research Area

The goal for HeC is to empower European clinicians to further advance their profession by using such a powerfully innovative tool - as the combined HeC vertically integrated database, knowledge discovery mechanism and decision support system promises to be - that it will also constitute the natural starting point for the accumulation of now-missing longitudinal records, at least as far as paediatrics is concerned. Such a mission requires a consolidated effort aimed at establishing links with existing networks of excellence, be they in the area of Grid-based health care applications, of decision support systems applied to biomedical records, or of paediatric research and health care.

Below is a list of projects/networks with which HeC had initially planned to liaise with and establish relations:

- The Paediatric Rheumatology International Trials Organisation (PRINTO) (www.printo.org), which includes 43 countries with more than 170 paediatric rheumatology centres worldwide. PRINTO is based in the HeC partner IGG, and its Chairman, Alberto Martini, plays an active role in the project.
- A life sciences project called PONT (Parallel Optimisation of New Technologies for Post-Genomics Drug Discovery)
- A life sciences project called ETUMOUR (Web Accessible MR Decision Support System For Brain Tumour Diagnosis And Prognosis, Incorporating In Vivo And Ex Vivo Genomic AndMetabolomic Data)
- An IST project called MULTIMOD (Simulation of Multiple Medical-Imaging Modalities: ANew Paradigm For Virtual Representation of Musculo-Skeletal Structures)
- An IST project called GRASP (Grid Application Service Provision)
- An IST project called MammoGrid (European federated mammogram database implemented on a Grid infrastructure)
- A NIH funded project that collects longitudinal MRI data on more than 500 healthy children, on a 6-year period to study how the brain develops in normal healthy children (<http://www.brain-child.org/>)

2.4.1 Planned activities for dissemination

A key attempt to achieve such strategic relations is a networking session proposed by HeC as part of the IST EVENT 2006 (Helsinki, 21-23 November 2006), which the Consortium is hopeful will be accepted. Organized within the framework of the Finnish Presidency of the European Union by the European Commission's Directorate-General for the Information Society and Media, the IST EVENT 2006 will constitute an important European gathering in the field of Information Society Technologies, coinciding this year with the launch of the EU's Seventh Framework Programme for Research and Development. Devoted to high-level policy discussions on what governments and public authorities can do to help ICT contribute to an innovative Europe, and based on a "bottom-up" approach through proposals by companies, research institutions and other organizations from across Europe, the IST EVENT 2006 will represent an excellent occasion to probe what kinds of links can be established by "Networking Data Integration and Application Developments in e-Health", as the title of the proposed HeC networking session reads.

The session will aim to analyse how data integration efforts and the development of advanced applications based on integrated data are evolving within current European e-Health projects, addressing as primary targets the partners of other Integrated Projects such as @NEURIST, ACGT,

COCOON, HEALTHAGENTS, SAPHIRE, SHARE, EuResist. The themes indicated by HeC for discussion are:

- Challenges in achieving horizontal and vertical data integration and in deploying clinical applications like knowledge discovery and decision support systems;
- The possible development of an "information market" within European healthcare systems (similarly to the direction followed by the British NHS);
- The launch of global initiatives (like Agoria in Belgium) that seek to catalyze the action of a large number of ICT actors in order to provide clinicians with new solutions and services based on e-Health platforms;
- The role of medical institutions and the medical profession in mixed (clinical-technological) research projects.

HeC plans to be present at the IST EVENT 2006, even in the case the proposed session is not accepted.

2.4.2 ICT-BioMed and EGEE Conferences

Initial contacts with a number of e-Health projects funded under the Sixth Framework Programme were also made during the HealthGrid conference in Valencia (June 2006) which was attended by the Deputy Chairman for IT within the Scientific Committee, Richard McClatchey and the Project Coordinator and ICT for Bio-Medical Sciences Conference held in Brussels on June 29-30, 2006, which the HeC Project Coordinator, the HeC Project Management Team Leader and the leader of the HeC WP12 on Decision Support Systems all attended.

In particular, three contacts appeared to be of significant interest:

- ACGT, also for its involvement in neuroblastoma, which aims to develop a Biomedical Grid infrastructure supporting seamless mediation services for sharing clinical and genomic expertise. It will help to identify more quickly and more efficiently the characteristics that determine what form of treatment best suits which patient;
- Prof. Norbert Graf, Director of the Department of Paediatric Oncology and Haematology of the Saarland University Hospital, for the SIOP 2001/GPOH-study on therapy optimization supported by the Deutschen Gesellschaft für Pädiatrische Onkologie und Hämatologie, which involves more than 100 paediatric departments in Germany, Austria and Switzerland.
- A third contact, established on the initiative of Fariza Tahi on behalf of the pole System@Tic – Paris Région, concerns IT developments applied to medicine in general, and not specifically to paediatrics. Namely, it is the FAME2 Project, which has Bull as its industrial leader, and which plans to realize a new generation of servers for high performance computing and data processing. This project will develop an XML database for the physiome (at the outset a renal physiome), using an XML management system called XediX developed by CEA, one of their partners. The database shall accommodate quantitative information on all aspects of renal physiology, especially those relevant to mathematical modelling of the kidney at any level of complexity. The data can be textual, numerical, images, videos, etc., and will concern all possible anatomical and functional data, specially genomic and proteomic data.

In the coming months before Helsinki, an earlier networking occasion between HeC and other Grid-based projects (EGEE, @NEURIST, BIOPATTERN) will be provided by the EGEE'06 Conference set to take place at the CERN in Geneva on September 26-29, within the Life Sciences section of the 'Users and Applications' track. The conference will be dedicated to the areas of heterogeneous

data integration, to the use of ontologies and to knowledge discovery, with the aim of identifying common services that would enhance EGEE functionality and provide the means to match the requirements of related projects. By that time HeC - still running only a testbed installation - will not have yet produced sufficient content to justify a full scientific session of interest for the GRID community; it will therefore limit itself to a presentation of the project outline, aiming to establish networking relationships with the other 15 or so projects which will have a similar level of experience with gLite 3.0.

2.4.3 Other occasions for clustering and cooperating with different projects

Other occasions for networking, in the second half of 2006 will be:

- the Gaslini International residential training course on Paediatric Rheumatology directed by Alberto Martini of HeC clinical partner IGG, to be held in Genoa on September 18-22, 2006, where there will be a presentation of the goals and the logic of HeC;
- the EuroBio Conference, which will be held in Paris on 25-27 October 2006. This conference, built on the well-established European Biotech Crossroads meetings, will be an important event, which, moving from the broad assumption that “Europe’s oil fields are vegetable not mineral” since “refining and synthesis will be biological processes”, will raise strategic questions such as whether “is it yet politically acceptable for the EU to invest in an industrial future rather than struggling to maintain its industrial past”. A specific session of particular networking interest for HeC will focus on innovative therapies based on new diagnostic and prognostic monitoring, based on genomics enabling predictive medicine, while cell and molecular therapies and vaccines shall provide potential new approaches to diseases;
- the 2nd IEEE International Conference on e-Science and Grid Computing, due to be held in Amsterdam on December 4 -6, 2006 designed to bring together developers and users of e-Science applications and enabling IT technologies from leading international and interdisciplinary research communities. The conference serves as a forum to present the results of the latest research and product/tool developments, and to highlight related activities;
- The 7th International Symposium on Biological and Medical Data Analysis (ISBMDA 2006), Thessaloniki, Greece December 7-8 2006, which aims to integrate interdisciplinary research from scientific fields such as statistics, biomedical informatics, information processing & management and knowledge discovery for biomedical data analysis and its link with medical practice through well defined case studies and examples.

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 on institutional web sites featuring HeC, to seminars/workshops showcasing the project.

2.4.4 An attempt at broader public awareness: Musicogenetica Festival

A special attempt at achieving a broader general public dissemination will be offered by a scientific meeting entitled “The Biology of Music”, which originates from the experience of the first edition of the “Festival of Music and Genetics” organized in Bologna in May 2006 by HeC partner EGF (www.musicogenetica.it).

The core idea of the Festival, summed up in the slogan “Races do not exist: all different, all related”, will be the starting point for the 2007 edition of the Festival, during which further attention will be devoted to the analogy between music and genetics, since they both appear to be useful tools for promoting the reciprocal understanding between populations. In this perspective, the EGF will develop an analysis of different languages and means of expression of human and animal cultures and of their evolution, all inevitably linked to biological evolution. The comparison between different cultures and genetics on the one hand, and the review of existing literature on these topics on the other, will provide the scientific basis of the meeting to be held in Bologna in May 2007.

Within this broad context, a session will be 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 proposed session should 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. Authorities, including, for instance, European Commissioner for the Information Society Viviane Reading, the Head or Deputy Head of the EC e-Health Unit, and the Italian Minister of Health Livia Turco, will be invited to attend a final roundtable, which would follow preliminary sessions dedicated to exploring future health care scenarios.

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).

2.4.5 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 end 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.

2.5 Research Community

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.

Knowledge sharing will also be 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 will be convergence: building consensus is an integral component of knowledge sharing. To achieve this objective, a series of thematic workshops will be held that will have 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 will be the HeC Technical Coordinator, whose role and tasks were recently approved by the HeC Governing Board.

HeC IT partners have begun to meet across various WPs from the beginning of the project. A first Workshop for Activities 2, 4, and 6, was organised at the CERN (Geneva) by the end of January, followed by a second one at the end of March, and a third one at the end of May. The 4th workshop will take place at MAAT G (Toledo) after the summer. During these meetings all people related to the same WP or Activity had the possibility to meet, discuss and work together; the minutes of the meetings were all uploaded on HeC website. HeC clinical partners also organized similar workshop activities, focusing on the cross-talk and exchange among the three medical domains tackled by the project. These meetings, held in Genoa, Paris and London, were attended by the HeC Clinical Coordinator, Giacomo Pongiglione, or his representative.

A technical review of all WPs will take place in July 2006 Chaired by Dorin Comaniciu, chairman of the Scientific Committee.

The HeC consortium is aware that the true strength of the initiative stems 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.

3 DISSEMINATION INSTRUMENTS

3.1 Communication design

3.1.1 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

3.1.2 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 and is now being finalised.

Here, examples of latest ppt protocols and business cards are given:



Figure 2 HEC .ppt templates



Figure 3 HeC business card

3.2 Internet presence

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. A second release of the website with an improved look and feel is currently being refined implementing the current (Plone-Zope) technology platform, whereby single partners will be able to independently upload documentation, images, etc., thereby remotely populating the web site with content.

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.

3.2.1 Public Website

The first release of the HeC portal has been put in place with a preliminary graphical look and feel chosen - two areas (public area and private area for cooperative work) are being used. The .EU Internet domain has been obtained and is redirected on the current address of the site. First summary information about the project has been published in the public area, plus information on forthcoming events/conferences of a general interest.

As alluded to in section 2.4.3, HeC 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.



Figure 3 The HEC project website homepage

The main elements foreseen in the website are :

- Information about the project
- Information about Partners.
- Downloading of public documents.
- Contact details.
- Downloading of related documents.
- Links of interest
- Newsletter publication

3.2.2 Restyling of Home and internal pages (screenshots)

A new look and feel is being finalised. In the following screenshots, the latest versions of both the new look and feel for the homepage and internal page are shown.



The screenshot shows the Health-e-Child website home page. At the top left is the logo. Below it is a navigation menu with links: Home, About, Partners, Contact, Document, Links, and Events. A search bar is located at the top right. The main content area features the title "Health-e-Child" and a subtitle: "An integrated platform for European paediatrics based on a Grid-enabled network of leading clinical centres". Below this are three bullet points describing the platform's goals:

- To gain a comprehensive view of a child's health by vertically integrating biomedical data, information, and knowledge, that spans the entire spectrum from genetic to clinical to epidemiological
- To develop a biomedical information platform, supported by sophisticated and robust search, optimisation, and matching techniques for heterogeneous information, empowered by the Grid
- To build enabling tools and services on top of the Health-e-Child platform, that will lead to innovative and better healthcare solutions in Europe:

 Three red square icons are listed below these points:

- Integrated disease models exploiting all available information levels
- Database-guided biomedical decision support systems provisioning novel clinical practices and personalised healthcare for children
- Large-scale, cross-modality, and longitudinal information fusion and data mining for biomedical knowledge discovery

 On the right side, there is a "UP-COMING EVENTS" section listing two conferences: "ICT-BIO" (Brussels, Belgium, 29-06-2006) and "Conference 'DILS 2006'" (European Bioinformatics Institute, Hinxton, UK, 20-07-2006). Below the events is a calendar for June 2006. At the bottom, there are logos for the European Union and IST (Information Society Technologies) and the text "Information Society Technologies - Integrated Project - Contract Number 027749".



This screenshot shows the same Health-e-Child website home page as above, but with a large, semi-transparent image of a young child's face overlaid on the left side of the main content area. The child is looking towards the camera. The rest of the page layout, including the navigation menu, search bar, and footer, remains identical to the previous screenshot.

3.2.3 Site Map (Web contents structure)

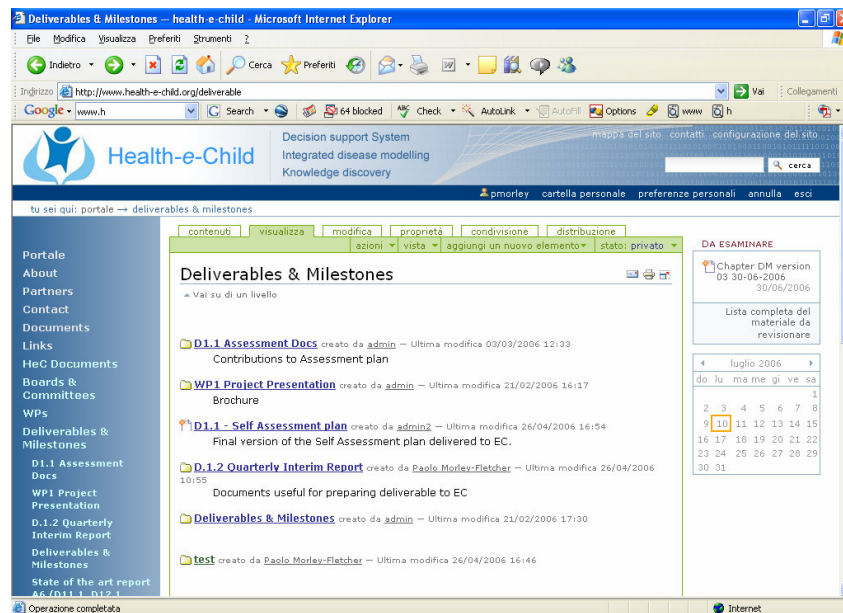
The existing contents structure is the following:

- [About](#)
 - [Mission](#)
 - [Description](#)
 - [Vision](#)
 - [Impact](#)

- [Partners](#)
- [Contact](#)
- [Documents](#)
- [Links](#)
- [HeC Documents](#)
 - [Background Documents](#)
 - [Contract](#)
 - [IP Consortium Agreement](#)
- [Boards & Committees](#)
- [WPs](#)
 - [WP1](#)
 - [WP2](#)
 - [Documents](#)
 - [Meetings](#)
 - [Deliverable](#)
 - [WP3](#)
 - [WP4](#)
 - [Meetings](#)
 - [WP5](#)
 - [Documents](#)
 - [Deliverables](#)
 - [Meetings](#)
 - [WP6](#)
 - [Links](#)
 - [Papers](#)
 - [Meetings](#)
 - [WP7](#)
 - [Documents](#)
 - [Meetings](#)
 - [WP8](#)
 - [Meetings](#)
 - [WP9](#)
 - [brain tumours](#)
 - [rheumatology](#)
 - [cardiology](#)
 - [meeting notes](#)
 - [WP10](#)
 - [WP11](#)
 - [WP11 meeting in Sophia, Feb 6 2006](#)
 - [Input / Output folder](#)
 - [WP12](#)
 - [Documents](#)
 - [Deliverables](#)
 - [Meetings](#)
 - [WP13](#)
 - [Meetings](#)
 - [References](#)
 - [WP14](#)
 - [WP15](#)
 - [WP16](#)
- [Deliverables & Milestones](#)
 - [D1.1 Assessment Docs](#)
 - [WP1 Project Presentation](#)
 - [D.1.2 Quarterly Interim Report](#)
 - [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](#)
- [D1.2 Quality Assurance Guidelines](#)
- [Workshops & Meetings](#)
 - [Meeting with Project officer 08/02/2006](#)
 - [Erlangen Kick-off Meeting 12-13/1/2006](#)
 - [Minutes and Presentations](#)
 - [Executive Board meeting 06/02/2006](#)
 - [WP11 meeting at INRIA 06/02/2006](#)
 - [Meetings at CERN 18th-24th March 2006](#)
 - [Brain tumor meeting Gaslini 06/04/2006](#)
 - [Meeting with Gaslini 16 May 2006](#)
 - [H-e-C Workshop at CERN 30/05-02/06/2006](#)
 - [Meeting at GOSH Tuesday 20 June 2006](#)
- [Events](#)
 - [Past Events](#)
- [News](#)
- [Admin & M-Lists](#)
 - [Project Netboard Platform](#)

3.2.4 Private Website (for collaborative work)



0.6.3. Restricted Websites

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 (an episode of this kind occurred in March 2006, because of the misuse of an automatic grabbing software by some project researchers).

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 softwares.

3.3 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.

3.4 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 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 eMail distribution for interested parties.

The newsletter will be issued quarterly, exclusively by e-mail. The target for issuing the first newsletter is September 2006. 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.

3.5 Brochure and posters

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 show 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.

3.6 Exhibit Booths

Although the project DoW made mention of plans to set up a HeC booth for exhibition purposes at numerous major conferences dealing with HeC-related subject matter, the idea has been disbanded because of inherent costs for construction of the booth itself, rental of exhibition space and staffing of the booth for the duration of an event. Funding resources permitting, the set up of an HeC booth at 2 or 3 select events during the project's lifetime will be evaluated on a case by case basis.

3.7 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.

3.8 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,*
- *International Journal Medical Image Analysis*
- *Methods of Information in Medicine*
- *Nature*
- *Neural Computation*
- *Neuroimage*
- *Paediatrics*
- *Proceedings of the National Academy of Sciences*
- *Rheumatology, Software Practice & Experience*
- *Studies of Health Technology and Informatics,*
- *The Journal of Computational Biology*
- *The Journal of Healthcare Information Management*
- *The Journal of Medical International Research*
- *The Journal of Pediatrics*
- *The Journal of Machine Learning Research*
- *The Journal of Rheumatology*
- *The Journal of the American College of Cardiology.*
- *Science*

3.9 International scientific conferences & workshops List

HeC has identified some relevant conferences, seminars and workshops to be held during its unrolling. Training seminars and workshops shall also be prepared in order to encourage input from external parties.

Some Possible Conferences:

European Association of Paediatric Cardiology, of the European Societies of Paediatric Neurology, Paediatric Radiology, Paediatric Research, Paediatric Rheumatology, and international symposiums such as Advanced Information and Telemedicine Technologies for Health, Biomedical Imaging, European Conference on Computer Vision (ECCV), HealthGrids, Magnetic Resonance in Medicine and Biology, Medical Image Computing and Computer-assisted Intervention (MICCAI), Human Brain Mapping, Medical Informatics, Molecular Imaging, Neuroscience

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. The idea is that as the technologies are put into place the various clinicians and medical professionals shall be put in a position to take advantage of them. Training is a good mechanism for reaching out and bringing external experts and users into the HeC realm, and is also a good mechanism for reaching in and creating a common understanding of disparate technologies and fields of medicine. A first event on “Genetics of Paediatric Inflammatory Diseases” has already been scheduled for April 2007, organized by WP 15 leader, EGF, in collaboration with HeC clinical partner IGG.

4 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 contacts with related projects
- 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.

Indeed, the guidelines for HeC dissemination have already allowed in its first six months of existence implementing or finalizing a number of a number of activities, including:

- the advance launch of a first release of the HeC web portal,
- the establishing of numerous initial contacts in the different research communities represented within the project,
- the planning of the publication of the project’s quarterly newsletter
- the planning of some initial networking activities and of a first tentative approach to raise awareness about HeC among a broader general public.

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.