Initial Dissemination Plan

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ABSTRACT: One of the key areas of the Advancing Clinico Genomic Trials on Cancer (ACGT) project is Dissemination and Outreach. In order for the project to fully succeed in achieving its ambitious vision and objectives it is vital to proactively raise awareness of the ACGT project, attract interest and ultimately participation from many different disciplines, the academic and research community and business.

This Initial Dissemination Plan outlines where dissemination effort will be concentrated during the next several months. It identifies a number of things, not least roles and responsibilities, potential audiences, messages, and methods of communication that should be used by WP15 partners and measures for success. This plan will be further revised at regular time intervals to (a) keep up with the evolution of project activities and results and (b) to take into consideration positive and/or negative experiences from dissemination activities undertaken.

KEYWORD LIST: Dissemination, Key Message Communication, Web Site

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1 Executive Summary

Dissemination is the responsibility of the Dissemination WP (WP15). The purpose of the Dissemination Plan is to provide a formal planning document for the various dissemination activities of the project for the next reporting period. To summarise, the Dissemination Plan provides guidance for using and disseminating knowledge throughout the project. The plan is not exhaustive but it is unlikely to change significantly in the future due to the fact that the communications objectives will largely remain the same for the duration of the project.

The Technical Annex identified the main objectives of WP15 as follows:

- To raise awareness of the benefits of ACGT to new user communities ensuring an appropriate message is delivered to each of them;
- To ensure new user communities know where and how to get involved in the project so they can be converted to real users;
- To ensure the information tools needed for each target audience are available and support the growth of many, varied, individual user communities;
- To identify and target new user community audiences and applications. The challenge is to reach new communities, such as new research disciplines, new industrial and commercial groups and branches of government. WP15 will need the assistance of ALL activities to help identify new user communities (see audiences for more detail).

The Dissemination Plan goes a step further than the Technical Annex and identifies in real terms what precisely needs to be done by WP15, when it needs to be done, why it is needed, how it can be achieved as well as providing some measures for success. The expected outcome of the activity will be the establishment, in conjunction with other Work Packages, of a large, well informed ACGT user community spanning many scientific and industrial disciplines that bring different applications to be used on the ACGT Framework.

WP15 Roles and Responsibilities

WP15 roles and responsibilities have been defined in the Technical Annex. The WP15 team consists of individuals from all involved institutions and the effort budgeted for corresponds to approximately 3 Full Time Equivalent (FTE). HealthGrid, as the lead partner, works closely with the Coordinators (ERCIM and FORTH) and with the Dissemination and Outreach partners. Each partner reports directly to HealthGrid and is responsible for ensuring that, among other things, localized web pages (where applicable), translation of news releases and publicity material distributed to them by HealthGrid, media relations, local events management, to identify target audiences within each domain and attempt to reach them via the various methods of communication available. WP15 partners must also provide HealthGrid with specific statistics of their dissemination activities for the official Dissemination Reports.

Audiences

The “main” audiences for the duration of the project will remain relatively static – patients, clinicians, scientists, researchers, media, industry, government. The difficulty for WP15 is that the number of potential audiences within these categories is huge. The Dissemination Plan aims to provide WP15 partners with guidance as to which domain they could be targeting in their own countries. The media will be a key audience for WP15 as it is through targeted media relations that the other audiences can be reached globally.

Roadmap

The Roadmap details the methods of communication that are already in place and can be used by all WP15 partners in order to disseminate information about ACGT. These methods include internal and external websites, conferences, events, mailing lists, publicity material and templates, media relations, government relations and newsletters.

Measurement and Evaluation

As communication is not an exact science and is intangible in many ways, it can be difficult to measure success. However, some key metrics for success were identified. The Plan aims to highlight what WP15 should measure, how and why. The metrics for success in this plan include: the number of events where ACGT is presented; the number of events where ACGT is promoted; a central mailing list to ensure contacts made at events, meetings and presentations are collected and all the key people kept informed about the project; feedback can be submitted in the form of questionnaires, and the number of website hits are available.

Conclusion

It is clear from the results of the first 9 months that WP15 did get off to a promising start in some areas of dissemination, i.e. scientific dissemination whereas delays in other dissemination activities of the project have been identified. Such delays were due to difficulties in finalising the ACGT branding and style which has caused some delays in producing dissemination material.

The major challenge for the next few months is ensuring all WP15 partners buy in to the Dissemination Plan and concrete “dissemination messages” are developed and effectively delivered to the potential target audiences of the project.

In assisting the Dissemination Team of the project for the development of the “project messages”, a central Editorial Board has been established by the Management of the Board, which has already begun delivering quality material for the various “general” dissemination activities of the project.

The methods of communication are also in place, which include:

- The External Website is up and running. It currently explains various aspects of the project, but will be further developed in terms of content in the immediate future so that it fully documents the various messages of the project.
- A wide-range of publicity material is available on the BSCW server (https://bscw.ercim.org). These include business cards, bookmarks, flyers, stand up poster…
- The internal (technical) website is up and running allowing individual activities to post items on their own pages for all those involved in the particular activity to share information;
- The ACGT style has been finalised (by HealthGrid, FORTH & ERCIM);
- Templates have been developed which allow WP15 partners to create their own generic posters, technical posters, Word documents (news releases and information sheets) and slide templates in the ACGT style (these are available to download from the BSCW website – https://bscw.ercim.org/);

In addition targets have been defined, which will assist the project to continually monitor and regularly evaluate the effectiveness of its dissemination strategy and plan, and introduce appropriate modifications if required.

2 Introduction to the document

2.1 Purpose of the document

The purpose of the Dissemination Plan is to provide a formal planning document for using and disseminating knowledge throughout the project (including target audiences and metrics for success). For a project of this size it is vital that all those involved have a clear understanding of what the aims of the dissemination activities are and what is realistically achievable. The plan highlights the key messages, potential audiences, roles and responsibilities, the methods of communication to be utilised as well as metrics for success.

2.2 Application Area

The target audience for this document is partners responsible for WP15 Dissemination, but it can also be used by other work packages (WP) as it gives a clear indication of what must be achieved and the methods proposed to achieve it.

2.3 Document amendment procedure

Amendment requests for this document must be send to Nathanael Verhaeghe, HealthGrid External Relations Officer, nathanael.verhaeghe@healthgrid.org and copied to webmasters@healthgrid.org

3 The different dimensions of dissemination

3.1 Introduction

It is our belief that dissemination has two distinct and different in nature dimensions. The first is scientific dissemination whilst the second is general dissemination to specific target audiences. These two dimensions are interleaved and, unavoidably, they influence each other.

3.2 Scientific dissemination

The dimensions of scientific dissemination are: scientific journal papers, scientific conference papers, liaison with SDOs (Standard Development Organizations), academic cancer work groups, white and position papers, etc

It is obvious that scientific dissemination can not be the responsibility of anyone else but those doing the scientific work. For this reason a large number of partners of the ACGT consortium have been assigned effort in WP15, mainly to fund their scientific dissemination activities.

3.2.1 Organization of the scientific dissemination of the project

The responsibility for the coordination of the scientific dissemination of the project lies with the scientific coordinator of the project and the Technical Management Committee, which has been established to assist him on issues related to the everyday technical management of the project.

3.2.2 Responsibilities of WP15

Following the previous discussion, it becomes obvious that WP15 can assist the scientific coordinator and the TMC by providing:

(a) a link to the most relevant scientific conferences, journals, etc to the project and online notification of relevant calls for papers, workshops, etc and

(b) a repository of the scientific dissemination of the project, i.e. PDF versions of papers and conference presentations made by the project, so that it can be accessible through the public web site of the project.

3.3 General dissemination

The general dissemination of the project is the task of WP15. General dissemination also has several dimensions and it will evolve as the project starts, matures, and approaches completion.

It is our belief that in order to define and execute an effective dissemination strategy and plan one must:

(a) Identify the messages that need to be conveyed

(b) Identify the target audiences to which the messages needs to be conveyed and

(c) Deliver the messages through appropriate and effective channels, taking into consideration the resources allocated to such an activity.

In the subsequent section we discuss these three dimensions and indicate work done today as well as the main planning for the next 12 months.

4 Main messages

Breakthroughs in genomics, proteomics, instrumentation and related technologies have created unprecedented abilities to observe, collect and generate data. These advances are transforming the life sciences from small-scale, hypothesis-driven experimental sciences into large-scale, data- and discovery-driven knowledge factories.

This transformation is in turn driving exponential growth in available data and thereby creating unprecedented opportunities for new drug discovery for those companies that can fully exploit the wealth of information. So why hasn't every company and research organization taken advantage of this? Existing infrastructures and cultures are not yet prepared to neither support nor exploit this rate of growth. The integration and transformation of data into information, and information into knowledge, is the key if the full promise of in-silico discovery is to be realized.

It has been widely stated and tacitly recognized that one of the biggest challenges in life science informatics and drug discovery today is data access and integration. This issue has become a major bottleneck to R&D productivity for many biotechnology and pharmaceutical companies.

Biological data sources are constantly changing, geographically distributed, diverse in data types and complex in structure. With the unprecedented growth of scientific data, the challenge has now become managing the complexity in order to allow researchers efficient access to the underlying information. This process is critical for turning data into knowledge - the crown jewels of drug discovery.

The ACGT vision and plan of work aims at enabling companies to fully exploit this valuable asset by providing a robust data integration platform to underpin and thereby facilitate all discovery-driven post-genomic research as well as (potentially) drug research and development initiatives.

Based on such an analysis we can confidently state that the main messages of the ACGT project relate to the opportunities presented, and the existing challenges which inhibit our capacity to harvest these opportunities.

(a) Opportunities of the research community to reduce mortality from cancer and improve therapies.

    Information arising from post-genomics research, and combined genetic and clinical trials on one hand, and advances from high-performance computing and informatics on the other is rapidly providing the medical and scientific community with new insights, answers and capabilities. The breadth and depth of information already available in the research community at large, present an enormous opportunity for improving our ability to reduce mortality from cancer, improve therapies and meet the demanding individualization of care needs.

(b) A critical set of challenges, however, currently inhibit our capacity to harvest these opportunities.

    Up to now, the lack of a common infrastructure has prevented clinical research institutions from being able to mine and analyze disparate data sources. This inability to *share* technologies and data developed by different cancer research institutions is therefore severely hampering the research process.

Most critically, however, even within a single laboratory, researchers have difficulty *integrating* data from different technologies because of a lack of common *standards* and other technological and medico-legal and ethical issues.

(c) Impact on post-genomic Clinical Trials.

As a result, very few cross-site studies and clinical trials are performed and in most cases it isn't possible to *seamlessly integrate multi-level* data (from the molecular to the organ, individual and population levels).

The project aims at improving quality of European clinical trials leveraging on latest advances in information technology and computer science. Although the targeted areas chosen are focused on Paediatric oncology and Breast cancer, the infrastructure which the project is aiming to develop and deploy could be easily exploited by and extended to any other disease area, after appropriate tailoring.

The targeted improvement in clinical trials is going to be achieved through a fully integrated handling of patient's biomedical profile, which requires a deep semantic integration of all data sources related to the subject involved in the trial, and by making this highly integrated set of data and computational assets available to end users with compelling user interface.

Apart from these high level messages that relate to the ultimate project objective, the project has other, intermediary objectives and outputs, which can be coupled to other more focused messages. Such messages, already apparent from the work done up to date in the project, relate to:

- Process and technologies for data pseudonymisation so that it can be shared.
- Training Pharmaceutical, Biotechnology and Clinical Research Organisations setting up secure Grid enterprise solutions
- The production of next-generation "CRF Creators" in compliance to a accepted "Master Ontology", which will be of relevance and interest to medical software companies.
- The "Master Ontology on Cancer" been developed by the project, which is of interest to Clinical Research Organisations and clinical trial software development companies
- Legal and ethical aspects related to the design and implementation of multi-centric post-genomic clinical trials, which are of direct interest to hospitals and other clinical research organisations
- In silico oncology scenarios simulating and predicting response to treatment in cancer will help to find the best treatment for an individual patient and will be of relevance for clinical trials in future
- Virtual reality visualization of clinical data and research data will help to better understand the malignant disease increasing the chance to find better treatments for patients
- The seamless integration of data will create knowledge based systems of a specific disease and will be of paramount interest to the whole audience of ACGT
- etc

5 Key audiences for the project

For an effective dissemination strategy, given the resource constraints of the project, it is very important to focus the dissemination activities to the appropriate audiences and target groups.

Currently, we have identified the following major categories of audiences:

- Medical professionals and researchers involved in translational research
- Patients and patient organisations
- Bioinformaticians and other IT system developers
- Pharmaceutical Companies and other industry
- Relevant national or international initiatives
- Academic cancer groups
- Regulatory Bodies
- General Public

The importance of these target audiences is not, obviously, the same. Medical professionals, life science researchers as well as bioinformaticians and other IT solution developers represent the most important target audiences of the project at this point in time. It is also evident that each of these target audiences requires quite specific and different in nature information with respect to the project. As a result the main messages will have to be adapted to the specific role and expectations of each of these target groups. Also, dissemination information has to be made available in several alternative ways, whenever possible.

5.1 Medical Professionals and researchers involved in translational research

5.1.1 Why?

Randomized controlled trials (RCTs) are a key source of evidence for medical practice. As a result the medical professionals involved in post-genomic clinical trial on cancer are the principal end users for the results of the ACGT project, so they are our priority. In order to support the main project objective of “open access” we need to reach out to this community with the objective to convince them to adopt the ACGT infrastructure for the contact of their clinical trials and the analysis of the collected data.

We need to disseminate to them about the project achievements, advantages, implications...

Life science researchers are experiencing a “data explosion” due to vast amounts of raw data being produced from both public sources and from high-throughput sequencing and other industrial-scale technologies being utilized in-house. This exponential growth curve is expected to continue. In fact, genomic data alone is now doubling every 12 months. From a scientific perspective, this wealth of data creates exciting and unprecedented opportunities for new discoveries (including new drug discovery). But being able to quickly and effectively turn this data into knowledge has proven to be a serious challenge and a concerting drain on drug R&D productivity.

Ironically, huge gains in efficiency in the “front end” of the discovery pipeline have created huge “down stream” inefficiencies because the data cannot be accessed, integrated, and analyzed quickly enough to meet the demands of drug R&D. The industry has outgrown traditional proprietary data capture and integration methods, and traditional “big IT” approaches solve only part of the problem. First generation integration solutions that centered on the concept of local repositories (silos, warehouses) have not scaled well, are costly to maintain, and ultimately are limited in long-term usefulness.

Further cluttering the landscape, researchers currently depend on proprietary “legacy” systems for warehousing, accessing and using their data. Huge investments have been made in applications that depend on the existing infrastructure, while these applications are constrained by the underlying limitations of the infrastructure. Key to moving forward is the ability to adopt *incremental* integration and access technology that allows the organization to overcome the limitations inherent in the underlying infrastructure while leveraging the huge investment in their existing research data and applications.

5.1.2 Main messages

The main message towards this community is the ACGT integration architecture as a response to this ever increasing challenge of data integration:

- ACGT will facilitate to run clinicogenomic trials by physicians by providing an infrastructure
  - that spares time in the overhead work needed for clinical trials
  - that offers the same portal regardless of the underlying trial
  - that fulfils all legal, ethical and regulatory demands and
  - that offers within the RCTs the best treatment a patient can get
- ACGT will help basic researchers by providing an infrastructure
  - that fulfils all legal, ethical and regulatory demands in clinical research
  - that offers the seamless integration of clinical data with research data and
  - that allows to answer clinical relevant question much faster

As the project matures and the vision (we believe) is gradually turned into reality, the messages will have to become stronger and stronger with the objective of motivating the community for uptake of the technology.

5.1.3 How to disseminate?

Apart form textual material available on the web site of the project, which will present existing challenges, the vision of the project and the main messages, ACGT has to be disseminated within scientific papers and on scientific meetings and congresses by all partners.

5.1.4 Material to produce

- website content
- on line visual demonstrators presenting the ACGT technologies and how they respond to real analytical and other discovery needs of clinical or life science researchers.
- scientific papers
- information sheets

5.1.5 Time line

- website content: T0 + 15
- information sheets: T0 + 18

- on line visual demonstrators: T0 + 24
- scientific papers: T0 + 48

5.1.6 Contributors

- Mainly WP 2 and WP12, but also all technical WPs

5.2 Patients and Patient Associations

5.2.1 Why?

The recruitment of patients in (post-genomic) clinical trials is perhaps the most expensive and challenging stage of the clinical trial process. Hospitals and pharmaceutical company investigators have a tedious and time consuming task, trying to locate patients whose profiles provide an adequate match for the complex trial inclusion/exclusion criteria.

Studies reveal that over 855 of all industry related trials fail to meet deadline, translating into estimated lost sales of $1.4 Million per day per trial[1]. With the number of patients required for participation in all types of clinical trials rising, there is an obvious need for a total revamping of existing recruitment practices.

On one hand it is difficult to enrol new patients in prospective randomized trials and on the other hand only 5-10 % of adults with cancer take part in such trials. There is on one side the “reluctance” of physicians to take part in clinical trials and on the other side the “unwillingness” of patients to be a participant of a trial. Both aspects have to be addressed.

For a lot of physicians clinical trials are only seen as something that is time consuming and not seen as a possibility to offer the best available treatment for their patients. Treating patients in clinical trials is not part of a quality process for physician, meaning that a physician does not need to offer a trial to a patient, even if a trial for his specific patient is ongoing. For a physician needs not to be aware of an ongoing trial in which he can register a new patient. He can treat his patient to the best of his knowledge and this is often outside of clinical trials.

Since the implementation of the EU Clinical Trials Directive (EU CTD), it became clear that even the well established clinical trial groups and national groups are struggling to meet the increased requirements of the EU CTD. A majority of clinical trials in cancer fall under the label “non-commercial” and they often have no specific funding. The increased expense of running non-commercial clinical trials has had a very inhibitory effect on clinical research in cancer in Europe. It is certain that this was not the intention of the EU CTD and the clear framework that the EU CTD has put in place is welcomed, nevertheless it has caused a barrier to the collaborative international trials of cancer. Due to different national interpretations of the EU CTD, solutions for running clinical trials in one country are found not to work in another, often preventing a second country from joining a study they would have taken part in the past. Sponsorship, insurance and indemnity are only two aspects that make investigator initiated trials more difficult to run today. This difficulty is a major aspect, why

[1] Reported in various presentations during the Clinical Trials Working Group Expo at MedInfo 2004

clinicians are more and more reluctant to open new randomized trials and enrol patients in prospective trials.

The knowledge about possible clinical trials and the initial information given to a patient for taking part in a clinical trial is most important and always critical in the way, that it determines to a high percentage the participation of a patient in a trial. One of the main reasons for the deficit in protocol enrolment is the lack of awareness by the public, community and healthcare systems that outcome for cancer patients may be better in clinical trials. However, physicians - inadequately trained or reluctant - have important responsibilities in this way.

Moreover, worldwide initiatives related to the linkage of molecular and clinical information in family-registries are also potential dissemination and collaboration targets for ACGT. Some indicative initiatives are listed below.

Registries linking molecular, familiar and clinical information

Themes/ Areas	International and European Networks, Projects and Collaborations	National Projects, Centres and Collaborations
General databases		**Generation Scotland** (UK) http://129.215.140.49/gs/Gindex.html **Italian Genetic Isolates network** isolati.projectpath.com **Estonian Genome Project** (EE) www.geenivaramu.ee/ **DeCode Genetics** (IS) www.decode.com/
Community genetics		**North Cumbria Community Genetics** Project (NCCGP) www.newcastle.ac & www.westlakes.org
Oncology databases	**InSiGHT** - International Society for Gastrointestinal Hereditary Tumours (Denmark Finland, France Germany, Iceland Norway, Sweden The Netherlands United Kingdom USA EU Collaborations) www.insight-group.org	Local or national **HNPCC** (Hereditary non-polyposis colorectal cancer)- and **FAP** (Familial Adenomatous Polyposis) registries in Denmark, Finland, France, Germany, Iceland, Italy, Norway, Sweden, The Netherlands, United Kingdom, USA (e.g. www.hnpcc.dk)
Congenital anomalies	**EUROCAT** – 43 registries in 20 countries including Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Netherlands, Portugal, Spain, Sweden, UK, Croatia, Hungary, Malta, Norway, Poland, Switzerland www.eurocat.ulster.ac.uk/	
Chronic diseases		**Rotterdam Study** www.epib.nl/ergo.htm
Twin studies	**GenomEUtwin** www.genomeutwin.org/ (Australia, Denmark, Finland, Italy, Norway, Sweden, The Netherlands, United Kingdom)	

Also, patient risk profiling and lifestyle management initiatives are also relevant ACGT dissemination targets (indicative initiatives are listed below).

Patient risk profiling & lifestyle management initiatives

Themes/ Areas	International and European Networks, Projects and Collaborations	National Projects, Centres and Collaborations
Projects	**PIPS** (Personalised Information Platform for Health and Life Services) http://193.178.235.132:8088/pips	**OLD@HOME** project Uppsala University (www.medsci.uu.se/mie/project/closecare/)
Cancer screening programmes	**InSiGHT** - International Society for Gastrointestinal Hereditary Tumours (Denmark Finland, France Germany, Iceland Norway, Sweden The Netherlands United Kingdom USA EU Collaborations) www.insight-group.org/	Local or national **HNPCC- and FAP-registries** in Denmark, Finland, France, Germany, Iceland, Italy, Norway, Sweden, The Netherlands, United Kingdom, USA

5.2.2 How to disseminate?

By

- providing information about benefits of prospective trials and the additional advantages of clinicogenomic trials in ACGT for physicians.
- providing information about the expected benefits to result form the quick execution of post-genomic clinical trials for patients and the society.
- taking active part in scientific meetings advertising ACGT to physicians for enrolling patients into clinical trials
- participate in patient meetings to inform patient groups and patients itself about the benefits of clinicogenomic trials within ACGT
- making sure that we document the strict security mechanisms implemented by the ACGT technologies and the procedures in place which make sure that they guarantee full compliance to the existing European legislation regarding management of sensitive personal data.

5.2.3 Material to produce

- web site content
- information sheets for patients and physicians
- Newsletter

5.2.4 Time line

- web site content: T0+15
- information sheets: T0+18

5.2.5 Contributors

- WP2 – information regarding research priorities of multi-centric post-genomic clinical trials on Cancer and the expected benefits.
- WP 10 – the legal framework existing
- WP 11 – the security dimensions adopted by the project, thus making the use of personal genetic data secure
- WP 14, WP16 – appropriately tailored training material

5.3 Bioinformaticians and other IT system developers

5.3.1 Why?

The main objective of the dissemination towards this target audience is to support the second principle of the project, i.e. open source. The challenge that we need to respond to is to gradually create a community of developers who accept the vision of the project, and become part of a large community of developers contributing analytical tools, algorithms and other technologies in compliance to the architectural specifications and the conformance guidelines of the project.

5.3.2 Main messages

"..We believe that it is timely to move bioinformatics from expensive, almost one-at-a-time, and "cottage-industry" towards twenty-first-century engineering practice, from which biologists obtain the customized software infrastructure they really want to have."[2]

Main ACGT message: join an important open infrastructure development effort that will increase exposure and usage of your modules

5.3.3 How to disseminate?

The main pillars of our dissemination plan to this community are:

- The vision and benefits of re-usable software services
- The ACGT Integration architecture and the conformance guidelines

Apart from general material available through the website, the main dissemination channel towards this audience is the scientific conferences, and workshops of the project.

Dissemination to vendors will strongly rely on technical and exploitation work packages, and it is a key factor for successful dissemination to listen to their needs. A good relation between HealthGrid and the previously mentioned work packages is therefore our focus.

5.3.4 Material to produce

- web site content on
  1. how to link to ACGT infrastructure development
  2. kinds of services to develop
  3. guidelines for developing ACGT compliant technology
  4. etc
- flyers/information sheets
- scientific papers

5.3.5 Time line

- web site content: T0+15
- flyers / information sheets: T0+18

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[2] M. A. Swertz and R.C. Jansen, Beyond standardization: dynamic software infrastructures for systems biology, Genetics, Vol. 8, March 2007, pp. 235-243

5.3.6 Contributors

The main contributors for this activity are WP3, providing the ACGT architecture and material explaining its rational, benefits and key technical aspects as well as WP9, providing the guidelines for integration with the ACGT architectural framework and conformance criteria.

5.4 Pharmaceutical Companies and other industry

5.4.1 Why?

If the project succeeds in achieving its objectives, pharmaceutical companies will be one of the main beneficiaries. Therefore, they represent a key audience for the project to talk to.

Similarly, other industries involved in the development of medical, or clinical trial software are also to benefit from the results of the project.

5.4.2 Main Messages

The main messages are, somewhat, similar to those to be developed for targeting the clinical researchers. Specifically important for the pharmaceutical companies are the following facts:

- Life science researchers are experiencing a “data explosion” due to vast amounts of raw data being produced from both public sources and from high-throughput sequencing and other industrial-scale technologies being utilized in-house. This exponential growth curve is expected to continue. In fact, genomic data alone is now doubling every 12 months.
- From a scientific perspective, this wealth of data creates exciting and unprecedented opportunities for new discoveries (including new drug discovery). But being able to quickly and effectively turn this data into knowledge has proven to be a serious challenge and a concerting drain on drug R&D productivity.
- Ironically, huge gains in efficiency in the “front end” of the discovery pipeline have created huge “down stream” inefficiencies because the data cannot be accessed, integrated, and analyzed quickly enough to meet the demands of drug R&D. The industry has outgrown traditional proprietary data capture and integration methods, and traditional “big IT” approaches solve only part of the problem. First generation integration solutions that centered on the concept of local repositories (silos, warehouses) have not scaled well, are costly to maintain, and ultimately are limited in long-term usefulness.

Post marketing surveillance of drugs and pharmacovigilance initiatives are also potential ACGT dissemination targets. Some indicative initiatives are listed below.

Post marketing Surveillance of Drugs and Pharmacovigilance[3]

Themes/ Areas	International and European Networks, Projects and Collaborations	National Projects, Centres and Collaborations
Organisations	**FDA**: Food and Drugs Administration Agency www.fda.gov/cder/handbook/postmark.htm **FDA** Drug Safety Oversight Board, www.fda.gov/oc/factsheets/drugsafety.htm **EMEA:** European Medicines Advisory Agency. **International Society for Pharmacoepidemiology** www.pharmacoepi.org	**GPRD**: General Practice research Database (UK) www.gprd.com
Centres		**Mayo Clinic** (US) www.mayoclinic.com **University of Groningen**, dept of Pharmacoepidemiology (NL), www.rug.nl Norwegian Institute of Public Health: www.fhi.no/eway **"PHARMO" Institute for Drug Outcome Research** (NL) www.pharmo.nl **Utrecht Institute for Pharmaceutical Sciences, Division of Pharmacoepidemiology & Pharmacotherapy** www.fhi.no/eway

5.4.3 How to disseminate?

The methods to be used include personal contacts and targeted electronic communication.

5.4.4 Material to produce

- Re-use of material developed for reaching other target audiences in the beginning.
- Customisation and specialisation of such material specifically for the pharmaceutical companies

5.4.5 Time line

- web site content: T0+18
- Customised flyers / information sheets: T0+24

[3] From the "Symbiomatics White Paper" (www.symbiomatics.org)

5.4.6 Contributors

- All WPs

5.5 Relevant national or international initiatives

5.5.1 Why?

The objective of ACGT is to provide a secure semantic grid infrastructure in support of integrated access and analysis of multi-level data, as created in the context of multi-centric post-genomic clinical trials on Cancer.

A number of initiatives related to the general Biomedical Informatics research domain also constitute targets for disseminating ACGT technology, achievements and results, as well as for potential collaboration. Such initiatives include projects, centres and networks some of which (the most indicative and known) are listed in the table below[4].

Projects	**@neurist**: Integrated Biomedical Informatics for the Management of Cereberal Aneurysms (www.aneurist.org)
	ASSIST: Association Studies Assisted by Semantic Interface Technologies (www.assist.iti.gr)
	I-Know: Integrating Information from Molecule to Man in Acute Stroke (www.cfin.au.dk)
	MATCH: Automated Diagnosis System for the treatment of Colon Cancer by discovering mutations on tumour suppressor genes (www.match-project.com)
	CGAP: An interdisciplinary NCI program to generate information and technological tools needed to decipher the molecular anatomy of the cancer cell (www3.cancer.gov/initiatives/cgap.html)
Centers	**US National Center for Integrative Biomedical Informatics** – University of Michigan (US; www.ncici.org)
	US National center for Computational Biology – University of California at Los Angeles (US; www.loni.ucla.edu/CCB/)
	US National Center for Biomedical Computing – Harvard University Informatics for Integrating Biology and the bedside (I2B2; Harvard medical School, US; https://www.i2b2.org)
Networks	**caBIG™**: The Cancer Biomedical Informatics Grid, NCI – a voluntary network of grid connecting individuals and institutions to enable the sharing of data and tools (US; http://cabig.nci.nih.gov)
	UK CancerGRID consortium (www.cancergrid.org)

[4] From the "Symbiomatics White Paper" (www.symbiomatics.org)

5.5.2 Main Messages

- The integrative nature of the platform and the benefits (in terms of work optimization) to be gained through its use

5.5.3 How to disseminate?

We will disseminate to regulatory bodies using the same strategy as with medical professionals.

5.5.4 Material to produce

- No additional material is required

5.5.5 Time line

- Contacts with relevant national or international initiatives will be done on a continuous base.
- Progress will be reported in the six monthly progress reports.
- Explain the 'critical path' issue and how ACGT could help make their approval process more efficient.

5.5.6 Contributors

- All WPs and partners

5.6 Regulatory Bodies

5.6.1 Why?

The dimension of trust and security of the infrastructure is of paramount importance, and a key aspect which will be disseminated towards bodies with regulatory function in the domain of clinical trials. The adherence to all legal and ethical legislation is an issue that needs to be disseminated very clearly towards these communities.

5.6.2 Main Messages

- The ACGT infrastructure is inline with the European legal and ethical rules and guidelines

- Argue about the level of security implemented in the ACGT technologies, and build confidence

5.6.3 How to disseminate?

We will disseminate to regulatory bodies using the same strategy as with medical professionals and to national and international initiatives

5.6.4 Material to produce

- website content
- flyers

5.6.5 Time line

- web-site content: T0 + 15
- flyers: T0 + 20

5.6.6 Contributors

- WP 3
- WP 10
- WP 11

5.7 General Public

Everyone is concerned by cancer, diagnosing and treating it. This is a subject receiving an increasing amount of attention. Disseminating to the general public will give them a first view of the ACGT project, and if one day they are more interested in the cancer area (by joining research sector, or directly concerned by a cancer...) they will have a positive first impression of the ACGT project and what it can provide.

5.7.1 Why?

It is important to raise the awareness of the general public on several of the critical research issues addressed by the project and convey results obtained.

5.7.2 How to disseminate?

Similarly to the others targets, we will use the website as a basis for dissemination. Then, as soon as we will have first results, we will write articles for magazines dedicated to a large public [annex 4].

5.7.3 Material to produce

- web site content
- popular articles
- newsletter

5.7.4 Time line

- web site content: T0+15
- articles: after T0+24

5.7.5 Contributors

- WP 2, WP8, WP12, WP10 & WP11

6 Initial dissemination achievements and plan

6.1 Scientific Dissemination

ACGT has already a good scientific output, as reported in detail in the six-monthly progress and the annual project reports. Our plan is to continue and increase the scientific production of the project *in a coordinated manner*. This is something we indeed expect to happen as the project matures.

Some key such dissemination activities are shown in the table below. A list of all publications done by the consortium can be found at the PAR for year 1 of the project.

Specific objectives have also been discussed and agreed upon, as reported in a subsequent section, i.e. 6.3.2, for the scientific production and dissemination of the project from now on.

Key Scientific Dissemination of the project	*Title and other details*
Journal articles	
(a) Methods Inf Med.	Maojo V, Garcia-Remesal M, Billhardt H, Alonso-Calvo R, Perez-Rey D, Martin-Sanchez F, Designing new methodologies for integrating biomedical information in clinical trials, Methods Inf Med. 2006;45(2):180-5.
(b) IEEE Transactions of Information Technology in Biomedicine Journal	M. Tsiknakis, M. Brochhausen, J. Nabrzyski, J. Pucaski, et al, A semantic grid infrastructure enabling integrated access and analysis of multilevel biomedical data in support of post-genomic clinical trials on Cancer, IEEE Journal on ITB (under review)
(c) Cancer Informatics	D.D.Dionysiou, G.S.Stamatakos, Applying a 4D multiscale in vivo tumor growth model to the exploration of radiotherapy scheduling: the effects of weekend treatment gaps and p53 gene status on the response of fast growing solid tumors, Cancer Informatics, 2: 113-121, 2006.
(d) Pediatric Surgery	Szavay P, Luithle T, Graf N, Furtwängler R, Fuchs J, Primary Hepatic Metastases in Nephroblastoma – A Report of the SIOP/GPOH Study, Pediatr Surg 41:168-172, 2006
(e) BMC Bioinformatics	P. Carmona-Sáez, M. Chagoyen, A. Rodríguez, O. Trelles, J. M. Carazo, A. Pascual-Montano, Integrated analysis of gene expression by association rules discovery,

	BMC Bioinformatics 2006, 7:54
(f) IEEE Transactions in Nano-Bioscience, Special issue on BioGrids	M. Tsiknakis, V. Maojo, G. Potamias, et al, Semantic grid services enabling ontology based integration and analysis of multilevel biomedical data, IEEE Transaction on Nano-Bio Science Journal (under review)

Referred Conference articles

(a) HealthGrid 06 Conference	M. Tsiknakis, et al, Building a European Biomedical Grid on Cancer: The ACGT Integrated Project, 2006
(b) 2nd International Advanced Research Workshop on In Silico Oncology: Advances and Challenges	N.Graf, A. Hoppe, What are the expectations of a Clinician from in Silico Oncology, 2nd International Advanced Research Workshop on In Silico Oncology: Advances and Challenges, September 25-26 2006, Orthodox Academy of Crete, Kolympari, Chania, Greece, p.36. URL: www.ics.forth.gr/bmi/2nd-iarwiso/
(c) IEEE Information Technology in Biomedicine Conference, 2006	M. Tsiknakis, Semantic Grid services in support of multi-centric, post-genomic trials on Cancer: Advances & Challenges, Ioannina, Nov. 2006
(d) HealthGrid 07 Conference	S. Rueping, et al, Extending Workflow Management for Knowledge Discovery in Clinico-Genomic Data, April 2007

Organisation of Scientific Workshops

Scientific workshops organised or co-organised	*Details*
(a) Scientific Workshop, May 30th 2006, Budapest, Hungary Theme: Advancing Clinico Genomics: Information Integration and Knowledge Dicsovery Issues.	**Co-organised with the ERCIM BMI WG** **(http://www.ics.forth.gr/bmi/ercim/events.html)**
(b) 2nd International Advanced Research Workshop on In Silico Oncology: Advances and Challenges**,** **25-26 September 2006, Kolympari - Crete, Greece.**	**Co-organised with the ERCIM BMI WG**
(c) Preconference workshop,IEEE Information Technology and	**Co-organised by ACGT in collaboration**

Applications in Biomedicine Conference (ITAB 2006), Nov. 2006	**with the the "SmartHEALTH"** **Integrated Project – (Full Title: Smart Integrated Biodiagnostic Healthcare), the "LOCCANDIA" Targeted Research Project - (Full Title: Lab – On – Chip profiling for CANcer DIAgnosis), and the "MATCH" Specific Targeted Project - (Full Title: Automated Diagnosis System for the Treatment Cancer by discovering mutations on tumor suppressor genes.)**

6.2 Planned scientific dissemination

6.2.1 Submission of Journal papers

The project will continue its policy of production and submission of scientific papers presenting its work and results in specific sub-domains of its R&D plan to high quality international journals. Specific targets set-up is reported in a following sub-section.

6.2.2 Participation with technical papers in relevant scientific Conferences

The project has made plans for active participation at international annual or biannual congresses by members of ACGT to present ACGT to the participants of these meetings. Most important are the following International conferences, which are attracting participants form the User Community of ACGT (i.e. clinical researchers involved in post-genomic translational research) and to which the project has made firm arrangements for its participation:

(a) European Cancer Conference (ECCO), Barcelona, Spain, September 23-27, 2007, (http://www.fecs.be/emc.asp?pageId=1228&Type=P)

The project has made arrangements for a 30 minutes presentation at the general meeting of the ***Breast International Group (BIG)*** that will take place at the ECCO conference in Barcelona. This BIG meeting will take place on Sunday the 23rd of September, from 10am to 4 pm and will involve 60-100 breast cancer oncologists over the world, except from the US.

A Management Board Meeting (MB) will be organized at the ECCO conference in Barcelona in 2007. The organizers from the Federation of European Cancer Societies (FECS) have been asked to officially put the ACGT MB Meeting into the program of the conference, since one of the topics of the ECCO meeting in 2007 is the translation of science into better clinical practice.

(b) Congress of the International Society of Paediatric Oncology (SIOP)
- The next congresses will be held in:
  - Mumbai, India, October 30- November 3, 2007,

    http://www.siop2007.in/

(c) Annual Meeting of the American Association for Cancer Research (AACR)
- The next meetings will be held in:
  - Los Angeles, CA, April 14-18, 2007,

http://www.aacr.org/page6899.aspx

- San Diego, CA, April 12-16, 2008

  http://www.aacr.org/page6901.aspx

(d) International Symposium on Biomedical Informatics, 25-27 June 2007, Barcelona

In addition, the project is in the planning phase for organising its participation in some of the following events, preferably with presentations.

(a) UPDATES ON BREAST CANCER Conference, Jul 12-14, 2007 | Bulgaria | Sofia

(b) GLOBAL SUMMIT ON INTERNATIONAL BREAST HEALTH CARE, Oct 01-04, 2007, Budapest, Hungary

(c) ADVANCES IN BREAST CANCER RESEARCH, Oct 17-20, 2007, USA, San Diego, CA

(d) 8TH PAN-EUROPEAN BREAST CANCER COALITION CONFERENCE, Oct 27-28, 2007, Amsterdam, Netherlands.

(e) 3RD ESH - EHA CONFERENCE ON FOCUS ON PAEDIATRIC HAEMATOLOGY AND ONCOLOGY, Sep 21-23, 2007, Sesimbra, Portugal

(f) 2007 INTERNATIONAL SOCIETY OF PAEDIATRIC ONCOLOGY (SIOP) ANNUAL CONGRESS, Oct 30-Nov 03, 200, Mumbai, India.

The project will also continue to disseminate through the annual HealthGrid Conferences, as well as through the IEEE EMBS Conference.

It will also continue its efforts in identifying additional relevant scientific events for participation and dissemination to targeted audiences.

6.2.3 Planned organisation (or Co-organisation) of Scientific workshops

Scientific workshops planned	Details
(a) 1st International WORKSHOP on Ontologies and Information Systems for the Semantic Web (ONISW 2007) **5-9 November 2007, New Zeland** (http://www.ischool.drexel.edu/faculty/hhan/onisw2007/)	Organised by FORTH and IFOMIS
(b) 1st Euro-American (Americano-European) Workshop on Virtual Tumor Development and In Silico Oncology to take place in Reykjavik, Iceland in **2008**.	Organised by ACGT (WP8) in collaboration with CViT (Center for Vitrual Tumor)

6.2.4 Planned organisation (or Co-organisation) of Training courses

Training courses planned	Details
(a) Training Course in Logic for Biomedical Research	This training course is organized by Barry Smith in collaboration with · ACGT - EU 'Integrated Project' Advancing Clinico-Genomic

This three-day training course is designed to provide a basic introduction to the field of biomedical ontology and to enhance awareness of current developments and best practices in ontology in the life sciences, focusing on logic and computational aspects. It will include a debate on the future role of OWL DL in biomedical ontology development.	Trials on Cancer, · European Network of Excellence Semantic Mining, · NCBO - US National Center for Biomedical Ontology, · RIDE - A Roadmap for Interoperability of eHealth Systems, · ECOR - European Centre for Ontological Research, · IFOMIS - Institute for Formal Ontology and Medical Information Science, Saarland University.

6.2.5 The ACGT Conference

Within the next 12 months an ACGT Conference will be planned and organised, possibly in collaboration with other similar initiatives.

6.2.6 Linking with similar initiatives globally

Performed

1. The project has already developed links with EGEE. We will continue to monitor the evolution of EGEE and regularly evaluate its implications for ACGT.
2. A joint meeting with the TransBIG ethical and legal group has also been fixed for the 15th of May. This meeting will take place at the Head Office of the EORTC in Brussels.
3. The US Cancer Biomedical Grid initiative (https://cabig.nci.nih.gov/). ACGT has participated in both annual conferences of caBIG with presentations (2006 – M. Tsiknakis, FORTH, 2007 – A. Bocur, Philips). It has developed specific links with key participants of caBIG and plans to continue to follow very closely the activities of caBIG, attend its annual conferences and built bi-later relations with additional key partners of this project.
4. ACGT has already established a formal relation with the “Center for Virtual Tumor – CViT”. Our plan is to exploit this cooperation for disseminating our approach to In-silico modelling on the relevant community in the US and worldwide.

   The following announcement on the center’s web site on October 2006 is indicative: “**October 16, 2006**: CViT.org announces a Strategic Partnership with ACGT. The Project on Advancing Clinico Genomic Trials on Cancer (ACGT) is part of EU's 6th Framework Program and represents a prominent research network of 25 institutions. (https://www.cvit.org/node/5)
5. The project has made arrangement for its participation on an Clinical Trial Ontology workshop planned to take place on the 16th -17th of May on the NIH Campus in Bethesda, USA. http://www.bioontology.org/wiki/index.php/Workshop_on_Clinical_Trial_Ontology. Prof Graf is making arrangements for the representation of ACGT.
6. UKs Cancer Grid, through the participation of Dr. Peter Maccallum, the CancerGrid Project Manager in the ACGT External Advisory Board. The main areas of interest are:
   - Metadata and ontology services;

- Trials models and management infrastructure;
- GRID technology;

7. The IST @nurist project, a sister project of ACGT. The technical management Committee of ACGT had a meeting with key representatives of the @nurist project. During the meeting, projects were presented, potential areas for common activities were identified and plans for such collaborations were drawn. Main areas of common activities are: ontology development, metadata and scientific approaches for the integration of heterogeneous biomedical data. It was agreed that a joint scientific workshop is to organised within the next 12 months.

Planned

1. The project has developed links with the "*Bio-Banking and Biomolecular Resources*" European infrastructure initiative. It is planning to participate in the next "Partner and Stakeholder Meeting, Vienna, March 17th, 2007" with the objective of presenting ACGT related work and strengthen links with the initiative.
2. Joined meeting with caBIG, Cancer Grid planned in June 2006 (Franscesca Buffa – University of Oxford plans to participate)

In addition, several partners have already planned a range of actions such as the ones reported below.

Partner 24: Hokkaido University

1. The university's relationship with ERCIM, in particular in connection with ACGT, will be reported in the next issue of Hokkaido University's monthly magazine.

2. Professor Tanaka is writing an article for the Japanese Scientific Monthly (a publication of the JSPS: Japan Society for the Promotion of Science), reporting on our activities under the grant that was awarded to support our participation in ACGT, and other European collaborations.

3. He also gave a briefing on ACGT in a high-level strategy meeting of the JST: Japan Science and Technology Agency.

4. Their involvement in ACGT has also caught the interest of the director of the NII (National Institute of Informatics, where Professor Tanaka is a visiting professor), who is keen to promote e-science projects.

Partner 25: IEO

They are starting ACGT-related research collaborations with other esteemed research institutes, among them:

1. World Health Organization - International Agency for Research on Cancer. They contacted prof. Peter Boyle, general director of WHO IARC, by explaining to him the aims of the projects and the objectives of the IEO partnership. He came at IEO and declared that WHO-IARC is extremely interested in collaborating, through the IEO partnership, to this project. In forthcoming weeks there should be a meeting to better finalize possible collaboration between the two institutions, in the framework of the long-standing collaboration between WHO-IARC and IEO.

2. The National Research Council of Italy, Institute for the Analysis of systems and Computer Science, in Rome. They contacted the research directors Prof. A. Bertuzzi

and Prof. A. Gandolfi, with whom the Epidemiology and Biostatistics division of IEO collaborate since may years, and they agreed to establish new ACGT-related research line in the field of mathematical modelling in Oncology.

3. The University of Pisa. The institute collaborates with some departments of that university, in particular with the departments of Mathematics and of Pharmacology. In January, Dr. A. d'Onofrio, during a one-week visit at the Mathematical Department, illustrated the main aims of ACGT project to the group "Mathematical Diagnosys", leaded by Prof. F. Giannessi. It has been agreed to collaborate, in the framework of ACGT-related research of IEO, both in the filed of system biology and of bio-informatics.

6.2.7 Linking with patient's associations and other such bodies

By complementing public actions towards better health and by collaborating with local and European authorities to fight cancer it is of utmost importance to coordinate this lobbying activities in close cooperation with patients and patient cancer organisations. Today for nearly every cancer a patient organisation is known. In the European context patients' coalitions did form Cancer leagues, to provide support to cancer patients and their relatives, and to improve the quality of treatment.

The **Association of European Cancer Leagues** (ECL) (http://www.europeancancer leagues.org/) is a federation of national and regional Cancer Leagues, made of either patients' coalitions or of cancer control professionals. The objectives of the association are to improve communication, to promote, enhance and co-ordinate collaboration between European leagues/societies and to foster fruitful activities between European cancer leagues and organisations, in order to reduce the growing cancer burden in Europe.

ECL is located in Brussels and is a non-for-profit association (asbl; association sans but lucratif), under Belgian law. ECL was created in 1980, and consists of 31 members today, located all over extended Europe (See Appendix 1 for a listing and details of members).

Regarding Paediatric Cancer the **International Confederation of Childhood Cancer Parent Organisations** (ICCCPO) was founded in May 1994 in Valencia, Spain. ICCCPO is a worldwide network of organisations of parents of children with cancer. The mission of ICCPO is to share information and experience in order to improve access to the best possible care for children with cancer everywhere in the world.

ECL as well as ICCCPO will be contacted by ACGT asking for collaboration and for providing names of persons, who will attend Management Board Meetings of ACGT. These representatives of the patient organisations should especially be enrolled in the discussion of legal and ethical issues. The goal is to strengthen the collaboration between patients and ACGT to foster fruitful activities in order to bring basic research faster into clinical practice.

Regarding ICCCPO there will be the next meeting at the SIOP conference in Mumbai in October/November 2007. ACGT is in contact with ICCCPO to arrange an informal meeting at this conference. In Germany **Mrs. Renate Heymans**, Deutsche Kinderkrebsstiftung in Bonn (www.kinderkrebsstiftung.de) is contacted and is in favour to support ACGT. Parents organizations from other European countries will be contacted during the ICCCPO meeting in Mumbai.

Mr Evert van Veen, a Dutch medical lawyer who has worked with the TubaFrost project funded under the EU Framework V programme, gave a presentation during the SIOP Nephroblastoma Committee meeting in London in February 2006. The key messages from his presentation were that TubaFrost had established and set a precedent that if tissue had

been collected and stored and/or processed according to national legal and ethical standards, then that material could be used for research in another country, even if that second country had more stringent requirements. He was happy to remain in contact with the group and provide advice should national co-ordinators encounter any difficulties in being able to provide samples to agreed projects for this trial sample set.

Also, contacts with EuropaDonna (Greek chapter) have been initiated and being pursued. Others to follow.

6.2.8 Linking with regulatory bodies, data protection agencies and the legal community

Performed

As it is vital for the success of ACGT to be in line with the European regulation, a first contact was established to the Art. 29 Working-group of the European Data Protection officers (http://ec.europa.eu/justice_home/fsj/privacy/workinggroup/index_de.htm) and the first results of our work were communicated to this group.

Further effort was made to make the main results of the legal/ethical research known to the legal and computational community. A workshop at the yearly conference of the German Computer Society ("Gesellschaft für Informatik") as well as several meetings of the German "Telematikplattform für Medizinische Forschungsnetze (TMF)" were attended with presentations on the legal/ethical framework of ACGT. Presentations were given at the CeBIT and at the yearly international congress on medical law. Several papers were published in leading journals on data protection and law.

Planned

The legal framework will be presented in detail to the art. 29 working-group and at all major events of ICT-law and medical law, for example during the CeBIT 2007 and 2008. A reviewed publication in an English-speaking international law journal on medical law is in preparation.

6.3 Measurement and evaluation of the effectiveness of the dissemination plan

6.3.1 Critical success factors

In order for the Dissemination Strategy to achieve its aim and contribute to the success of the ACGT project a number of factors need to be addressed:

- **FAMILIARISE**: It is vital that all WP15 partners familiarise themselves with the Dissemination Plan and identify the areas within their countries that need to be addressed.
- **FOCUS:** Everyone involved with dissemination should concentrate their efforts on what and who really matters. Bigger is not necessarily better!
- **COMMUNICATION WITHIN WP15 and the editorial board:** For a project of this nature it is vital that WP15 partners keep talking to each other. Meetings will be held

via phone to help close the communication gap, in addition to any necessary telephone and email contact.

- **COMMUNICATION WITH OTHER ACTIVITIES:** It is imperative that other activities keep WP15 and HealthGrid informed of progress in the project.
- **GUIDANCE, SUPPORT AND ASSISTANCE:** WP15 is a team and as such, we are there to support, guide and assist each other when required. In other words, if you need help, don't be afraid to ask!
- **RESOURCES:** The task is huge, the resources are not. This means that it is not always feasible to do everything we would like to do (or indeed are asked to do by those involved in other activities). We should, however, ensure that what we do, we do it well!
- **SUCCESS OF OTHER PARTS OF THE PROJECT:** Of course, WP15 can only disseminate information that is relevant, timely and progressive so are at the mercy of other activities to make progress in their own areas and to inform WP15 members of such progress.

6.3.2 Measurable Indicators

Communication is not an exact science and it is very difficult to measure success as it is intangible in many ways. However, it is important to set some metrics for success in order to know if the project and WP15 is achieving its aims. In order for the work related to this activity to be assessable, we need to set up some sort of measurable indicators by which we can evaluate the degree of success. The indicators defined below will be monitored and status information will be reported in subsequent Dissemination Reports of the project.

The measurable indicators agreed are:

(a) **Scientific Journal Publications**: 4-5 submitted scientific publications on selected aspects of the technical-scientific dimensions of the ACGT project during the next 12 months.

(b) **Papers in Scientific Conference**: At least one scientific conference publication by each technical/scientific WP of the project during the next 12 months.

(c) **ACGT Conference**: Organization of an ACGT Conference within the next 12 months

(d) **Organization (or co-organisation) of Scientific Workshops**: The objective is to organize, or co-organize, in collaboration with other relevant projects/initiatives, three (3) scientific workshops on topics relevant to the workplan of ACGT during the next 12 months.

(e) **Record of Contacts in the project Knowledgebase**: keeping a central record of contacts made at events, meetings and presentations and adding them to the ACGT mailing list to receive news releases/newsletters

(f) **Number Count of Publicity Material:** a simple "number-count" exercise in relation to number of publication, project brochures, flyers produced and disseminated

(g) **Events:** events where ACGT is promoted (where ACGT publicity documents are handed out) and/or presented (someone gives a formal presentation about ACGT)

will be recorded. At a minimum, these records will provide an idea of the potential audiences reached.

(h) **Website Hits:** the number of website hits and the number of unique visitors will indicate how many people are visiting the ACGT portal and websites.

(i) **Editing of a Scientific Book:** Within the next 12 months the consortium will conclude all required agreements for the production of a Scientific Book on “Post Genomic Clinical Trials on Cancer: Technologies and Challenges”.

We, obviously, recognize that these are measures driven by ‘us’ ie pushing. The real and hard to answer issue is how we “measure” the STAKEHOLDERS perception of the project over time. Based on our initial experiences from talking to stakeholders, we will formulate appropriate indicators during the next phase of the project.

6.4 Evolution of the dissemination strategy and plans

For a project of this size and geographic diversity, it is vital that the key messages of the dissemination campaign remain consistent. It is envisaged that the key messages will predominantly come from the Management Board of the project. These in turn will be passed on to HealthGrid and to the editorial board, for refinement and production of appropriate material customised to specific target audiences.

Some key messages may be generated at local levels. WP15 partners are asked to inform HealthGrid if this happens to discuss the best way to proceed as the messages may be used as a stepping-stone to create publicity at the wider European level

In the early stages of the project the messages are more “general” but it is likely that in the later stages of the project, messages will be become more specific especially when targeting specific audiences.

It is also natural to expend that “messages” will need to be updated, like the information concerning tools or legal and ethical aspects for example, and we need to be ready to update these messages. In order to be reactive in this area, the dissemination team needs to stay close to the management and the editorial board.

7 The dissemination instruments of the Project and other activities

In order for our dissemination strategy to be

- coherent
- targeted
- effective and
- efficient

the project needs to establish (and has already done so) appropriate dissemination instruments and allocate concrete responsibilities.

The bodies established, the dissemination instruments set up and the responsibilities assigned are described in the following sections.

7.1 The Editorial Board

The editorial board has been established following a Management Board decision. Its role is to assist the WP Leader and the Management in the production of required material for the general and targeted dissemination of the project.

Name	Organisation
Norbert Graf	**University of Saarland**
Christine Desmedt	**Jules Bordet Institute**
Francesca Buffa	**Oxford University**
Dimitris Kafetzopoulos	**Institute of Molecular Biology and Biotechnology, FORTH**
George Stamatakos	**ICCS/NTUA**
Andreas Persidis	**Biovista**
Regina Kollek	**UoH**
Alberto D'Onofrio	**IEO**

7.2 Corporate Style and Branding

In order for ACGT to be easily recognisable as the main Cancer Project in Europe, it was imperative to build a strong corporate image, brand and style. This takes slightly longer to finalise than anticipated and should be ready by March 2007.

The style and branding is built around the ACGT logo designed by FORTH. It will include a Word document template, a generic poster template, technical poster templates (in portrait and landscape) and a slide template. All the templates will be available to download via the BSCW website. A style guide will be written to explain what can and cannot be done with the brand which will assist WP15 partners to adapt the material to their own language and localised style. It is imperative that everyone within WP15 ensures that anyone using the ACGT branding does so in line with the style guide in order to preserve ACGT as an easily recognisable brand.

Although the official language of the project is English, the idea is to ensure ACGT material is widely available across Europe (and the rest of the world) in different languages where possible. If WP15 partners are using English, they should ensure they use English UK, rather than English US.

7.3 Websites

7.3.1 Main website – http://www.eu-acgt.org

The above URL should be used at all times when referring to the ACGT website. The portal will give users the opportunity to enter the public site (external) or training site. Those WP15 partners will own localized web pages and should also ensure that the ACGT portal page is prevalent on their sites.

Keeping the information up-to-date is a continuous process and input from partners will be essential, particularly regarding news items. WP15 partners are also required to give HealthGrid all the documentation that is translated so that it can be added to the website. Other activities (via the Editorial Board and the Management Board) are required to assist. HealthGrid in ensuring up-to-date information is on the site about areas within their own activities, particularly technical information.

An intranet needs to be build to help keep the web site up to date, and to keep the dissemination efforts at maximum capacity as well to propose new events...

This intranet will be available during the month 15 of the project.

It is true that the web site of the project, although available, did not fulfil its function as the main point for the general project dissemination at the beginning. To a large extend, this is the result of the very interdisciplinary nature of the project and its complexities.

It became apparent to the management of the project that in order to be effective in this dimension support of the main dissemination group was needed. It responded by establishing an Editorial Board at the project level, which has assisted substantially in the production of quality material (in terms of content and language) and its publication through the project web site.

7.3.2 Training Website

The Training website is to be maintained by the Training Activity (i.e. WP14) and forms part of the main portal of the project. WP14 is also responsible for updating the Training Events section on the public site.

7.3.3 Wiki Website

The Wiki website is been maintained by the HealthGrid and forms part of the main portal page. A wiki website is one of the best ways both to support internal collaboration, document decisions and the discussions leading to taking such decisions as well as to stimulate, in the future, involvement of a wider community to ACGT.

7.4 Mailing lists

The WP15 leader has undertaken the responsibility to gradually compile and continuously update a large mailing list with contact details of all those of relevance to ACGT. This list will be utilised for the electronic news feed (i.e. Newsletter) of the ACGT dissemination campaign.

7.5 Newsletter

The project has decided to move towards the design and production of an electronic Newsletter to be produced Quarterly, through which it will pass the main messages to the target communities.

7.6 ACGT Conferences

The first ACGT conference is foreseen to be held within the next 12 months and possibly in conjunction with another appropriate and well know in the field event. The ACGT conferences will predominantly be held to give ACGT staff the opportunity to meet face-to-face, although “external” audiences are also encouraged to attend. The conferences are primarily managed by HealthGrid, FORTH and ERCIM but the WP15 partners are expected to help publicise these events both within their countries and to wider audiences through media relations, advertising on their websites and publicity.

7.7 Other Events

Another way to reach wider audiences is to ensure ACGT is publicised at events where known target audiences attend. HealthGrid will develop generic posters (templates that can be adapted locally) which can be used in conjunction with publicity material for stands at these events. WP15 partners will be responsible for ensuring that the stands are equipped with the relevant material and indeed “manned” where applicable.

Each partner is expected to keep a detailed list of all the events attended where ACGT is promoted and/or presented (including other activities within their countries). WP15 partners are asked to keep a detailed log of the events and include country, dates, places, tool (e.g. presentation or interview) and person(s) responsible. Presentations should be sent direct to webmasters@healthgrid.org who is in the process of building a central database.

It is possible that contacts will be made at these events. WP15 partners are expected to keep a record of all such contacts and inform HealthGrid of these individuals for the dissemination reports and for the mailing list for newsletters and press releases.

7.8 Internal Mailing Lists

ERCIM maintains ACGT mailing lists except external dissemination mailing lists which will be directly managed by HealthGrid.

There is a generic WP15 mailing list for ALL WP15 partners and any individuals who are responsible for dissemination but are not currently on the list should inform HealthGrid immediately. The WP15 email address is acgt-wp15@inria.fr.

A central mailing list has recently been set-up for people wishing to hear more about ACGT. The people on this list will be kept current on the ACGT progresses. WP15 partners are asked to either send the newsletter to their own lists or provide HealthGrid with the relevant email addresses so they can be contacted centrally. The mailing list is newsletter@eu-acgt.org .

7.9 Publicity Material

ACGT flyers and bookmarks have been printed and are provided to partners “free of charge” by HealthGrid within budget limits. Templates for these materials have been made available for personalisation by partners. All material should preferably be printed in colour. There are plans to develop more publicity material, including a quality brochure which can be used for general dissemination, postcards and stickers.

The majority of publicity material has been developed by HealthGrid and will continue to be (but with the active participation of the Editorial Board and the Management Board), and then distributed for translation. However, when required, WP15 partners need to produce their own. When this arises it should be discussed with HealthGrid to ensure no repetition of effort or resources.

7.10 Media Relations

Media briefings and press conferences will be held when there is something newsworthy to say. These will predominantly happen around the ACGT Conferences and will be handled by HealthGrid, FORTH and ERCIM, although input from other partners will be important for inviting journalists from their countries and generating interest in the briefings and conferences. There may be occasions when WP15 partners feel they have something local worthy of a conference or briefing. If this is the case, the partner should liaise directly with HealthGrid to ensure the right ACGT spokesperson attends the briefing or conference.

7.11 Documentation

WP15 partners are also asked to ensure that photographs taken at events where ACGT is publicised are sent to HealthGrid (clearly captioned with when and where the event took place) to help build an ACGT “visuals” database. The photographs will then be made available via the internal website and can be used by all WP15 partners for publicity purposes. The HealthGrid WP15 contingent is also planning to develop a “graphics” library. If WP15 partners have anything that can be included in this, they should send it to webmasters@healthgrid.org. Similarly, WP15 partners can write articles about events and

publish them directly on the website after logged in or send them to HealthGrid who will post them on the ACGT portal as news items.

7.12 Relationships and Responsibilities

WP15 roles and responsibilities have been defined in the Technical Annex. The WP15 team consists of some 50 individuals from 25 institutions which correspond to approximately 3 Full Time Equivalent (FTE). HealthGrid, as the lead partner, works closely with the Coordinators (ERCIM and FORTH) and with the Dissemination and Outreach partners. Each partner reports directly to HealthGrid and is responsible for ensuring that, among other things, localized web pages (where applicable), translation of news releases and other publicity material are distributed to them by HealthGrid, media relations, local event management, to identify target audiences within each domain and attempt to reach them via the various methods of communication available. WP15 partners must also provide HealthGrid with specific statistics of their dissemination activities for the official Dissemination Reports.

The formal EU deliverables for WP15 have been, and will continue to be, coordinated by HealthGrid. When required, the WP15 partners are asked to contribute to the deliverables.

Table 1: WP15 Partners

Table 1 provides an overview of WP15 representation and identifies the individuals working on WP15.

Participants	Contact Name	Effort (first 18 months)	Effort (full project)
ERCIM	Rémi Ronchaud	2	6
FORTH	M. Tsiknakis & George Potamias	1,5	4
INRIA	Dominique Lavenier	1	3
UvA	R.G. Belleman	1	3
Philips	Anca Bucur	3	11
IJB	Christine Desmedt	1	3
SIB	Thierry Sengstag	1,5	4
LundU	Jari Häkkinen	1	3
UMA	Oswaldo Trelles Salazar	1	3
UPM	Luis Martín	2	6
FHG	Stefan Rüping Stephan Kiefer Gabriele Weiler	2	6

BIOVISTA	Andreas Persidis	1	3
UOC	Antonia Akoumianaki	1	3
UHANN	Nikolaus Forgó Tina Krügel	1	3
PSNC	Jarek Nabrzyski	1,5	4
Custodix	Brecht Claerhout	2	6
HealthGrid	Aurélie Fourré Nathanael Verhaeghe Nicolas Spalinger Pierre Bernat Romain Tartière	8	27
ICCS	Georgios Stamatakos	1,5	4
USAAR	Norbert Graf Matthias Brochhausen (IFOMIS)	2	2
SIVECO	Radu Gramatovici	1	6
FUNDP	Jean-Marc Van Gyseghem	1	3
UoH	Imme Petersen	1,5	5
UOXF	Francesca Buffa	1,5	4
UHok	Aran Lunzer Yuzuru Tanaka	1,5	4
IEO	Gordon McVie	1	3

Table 1 - WP15 Participants list

7.13 Time line for the production of required dissemination material

The text below presents at a glance the planned time-line for the production of the material required to support the planned activities described in previous section.

Time	**Objectives**
T0 + 15	Web site content adapted to audiences

Dissemination intranet launch

Design of the ACGT Newsletter

T0 + 18 1st issue of the ACGT Newsletter published

Posters:

- Medical professionals
- Technology and tool developers
- Post-genomic researchers

Flyers:

- Medical professionals

Information sheets:

- Patients
- General public

T0 + 20 Flyers:

- Regulatory bodies

T0 + 20 2nd issue of the ACGT Newsletter

T0 + 24 CD-Rom:

- On line demonstrations of the ACGT tools and services accessible through the project public website

8 Appendices

Although some of the identified contacts of relevance to ACGT, presented in the Appendices of this document, have also been included in other project documents, they nevertheless are included in the current deliverable for completeness.

Subsequent versions of WP15 Deliverables will provide updates on these contacts and other details wrt to how project dissemination activities are received by such audiences.

8.1 Appendix 1: Contact details of organisations of the European Cancer League

BELGIUM

Belgian Federation Against Cancer
(www.cancer.be)
479 Chaussée de Louvain
1030 Brussels, Belgium
Tel:+32 2 736 99 99
Fax:+32 2 734 92 50
E-mail: commu@cancer.be

Flemish League against Cancer
(www.tegenkanker.net)
Koningsstraat 217
B-1210 Bruxelles, Belgium
Tel: + 32 (0) 2 227 69 69
Fax: + 32 (0) 2 223 22 00
E-mail: vl.liga@tegenkanker.be

CROATIA

Croatian League Against Cancer
Illica 197
10000 Zagreb, Croatia
Tel:+385 1 3775 572
Fax:+385 1 3775 568

CYPRUS

The Cyprus Association of Cancer Patients and Friends
(www.cancercare.org.cy)
PO Box 23868
1687 Nicosia, Cyprus
Tel:+357 2 345 444
Fax:+357 2 346 116
E-mail: caocpat1@cytanet.com.cy

The Cyprus Anti-Cancer Society
(www.anticancersociety.org.cy)
PO Box 25296
1308 Nicosia, Cyprus
Tel: +357 2 249 7373
Fax: +357 2 231 6822
E-mail: vassilis.i@anticancersociety.org.cy

CZECH REPUBLIC

League Against Cancer Prague
(www.lpr.cz)
Na Slupi 6
12842 Praha 2, Czech Republic
Tel:+420 2 249 19 732
Fax:+420 2 2491 9732
E-mail: lpr@lpr.cz

DENMARK

Danish Cancer Society
(www.cancer.dk)
Strandboulevarden 49
DK-2100 ø Copenhagen, Denmark
Tel:+45 35 25 75 00
Fax:+45 35 25 77 01
E-mail: info@cancer.dk

Faroese Association Against Cancer
(www.krabbamein.fo)
J. Paturssonargota 24
FO-100 Tórshavn, Faroe Islands
Tel:+298 317 959
Fax:+298 315 727
E-mail: ffk@post.olivant.fo

FINLAND
Cancer Society of Finland
(www.cancer.fi)
Liisankatu 21 B
FIN-00170 Helsinki 17, Finland
Tel:+358 9 135 331
Fax:+358 9 135 1093
E-mail: society@cancer.fi

FRANCE
Ligue Nationale contre le Cancer
(www.ligue-cancer.asso.fr)
14 rue Corvisart
75013 Paris, France
Tel: +33 1 53 55 24 00
Fax: +33 1 43 36 91 10
E-mail: naudc@ligue-cancer.net

GERMANY
Deutsche Krebshilfe
(www.krebshilfe.de)
Postfach 1467
53004 Bonn, Germany
Tel: +49 228 72990-0
+49 228 72990-11
E-mail: deutsche@krebshilfe.de

Deutsche Krebsgesellschaft
(www.krebsgesellschaft.de)
Steinlestrasse 6
D-60596 Frankfurt, Germany
Fax: Tel:+49 69 63 009 60
Fax:+49 69 63 00 96 66
E-mail: beck@krebsgesellschaft.de

GREECE
Hellenic Cancer Society
(www.cancer-society.gr)
A. Tsoha 18-20
GR-11521 Athens, Greece
Tel:+30 1 6456 713 – 715
Fax:+30 1 6410 011
E-mail: hellas-cancer@ath.forthnet.gr

Hellenic Society of Oncology

11 Valtetsiou St.
10680 Athens, Greece
Tel:+30 1 362 5637
Fax:+30 1 3611 774
E-mail: HSO@ath.forthnet.gr

HUNGARY
Hungarian League Against Cancer
(www.rakliga.hu)
Post Box 7
1507 Budapest, Hungary
Tel:+36 1 225 16 21/22,23
Fax:+36 1 202 4017
E-mail: rakliga@matavnet.hu

ICELAND
The Icelandic Cancer Society
(www.krabb.is)
P.O.Box 5420
IS-125 Reykjavik, Iceland
Tel:+354 540 1900
Fax:+354 540 1910
E-mail: gudrunag@krabb.is

IRELAND
Irish Cancer Society
(www.cancer.ie)
5 Northumberland Road
Dublin 4, Ireland
Tel: +353 1 2310 500/Fax: +353 1 2310 555
E-mail: reception@irishcancer.ie

ITALY
AIMaC Associazione Italiana Malati di Cancro, parenti i amici (www.aimac.it)
Via Barberini 11
I-00187 Rome, Italy
Tel: +39 06 482 5107
Fax: +39 06 4871 492
E-mail: info@aimac.it

Lega Italiana per la lotta Contro I Tumori
(www.legatumori.it)
Via A. Torlonia, 15
I-00161 Rome, Italy
Tel:+39 06 44 25 971
Fax:+39 06 44 25 97 32
E-mail: sede.centrale@legatumori.it

LUXEMBOURG
Fondation Luxembourgeoise (www.cancer.lu) contre le Cancer
209, route d´Arlon
L-1150 Luxembourg
Tel:+352 45 30 33 1
Fax:+352 45 30 3333

E-mail: flcc@pt.lu

THE NETHERLANDS
Association of Comprehensive Cancer Centres (www.ikc.nl)
P.O Box 330
9700 AH Groningen, The Netherlands
Tel. +31 50 521 59 00
Fax +31 50 521 59 99
E-mail: r.otter@ikn.nl

Dutch Cancer Society
(www.kankerbestrijding.nl)
Sophialaan 8
1075 BR Amsterdam, The Netherlands
Tel:+31 20 57 00 550
Fax:+31 20 67 50 302
E-mail: info@kankerbestrijding.nl

POLAND
Polish Anti-Cancer Committee
5 Roentgena Street
02-781 Warsaw, Poland
Tel:+48 22 643 93 79
Fax: +48 22 643 90 63
E-mail: zwronkowski@coi.waw.pl

SLOVAKIA
League Against Cancer in Slovakia
(www.lpr.sk)
Spitalska 21
812 32 Bratislava, Slovakia
Tel:
Fax: +42 1 252 921 735
E-mail: lpr@rainside.sk

PORTUGAL
Liga Portuguesa contra o Cancro
(www.ligacontracancro.pt)
Av. Columbano Bordalo Pinheiro, 57-30 F
1070-061 - Lisboa
Portugal
Tel: +351 21 722 1810/ Fax: +351 21 726 8059
E-mail: info@ligacontracancro.pt

SLOVENIA
The Association of Slovenian Cancer Societies
Zaloska 2
1000 Ljubljana, Slovenia
Tel:+386 01 4309 780
Fax:+386 01 4309 785
E-mail: MZakelj@onko-i.si

SWITZERLAND
Swiss Cancer League
(www.swisscancer.ch)
Effingerstrasse 40
CH-3001 Bern, Switzerland
Tel:+41 31 389 91 14
Fax:+41 31 389 91 60
E-mail: info@swisscancer.ch

TURKEY
Turkish Association for Cancer Research and Control
Atac Sokak No:21
06420 Yenisehir-Ankara
Tel:+90 312 431 29 50
Fax:+90 312 431 39 58
E-mail: tkutluk@tr.net

UNITED KINGDOM
Cancer Research UK
(www.cancerresearchuk.org)
61 Lincoln´s Inn Fields
London WC2A 3PX
United Kingdom
Tel:+44 20 7242 0200
Fax:+44 20 7269 3100
E-mail: claire.mallinson@cancer.org.uk

Macmillan Cancer Relief
(www.macmillan.org.uk)
89 Albert Embankment
SE1 8UQ London
United Kingdom
Tel: +44 020 7840 7840
Fax: +44 020 7840 7841
E-mail: jsimpson@macmillan.org.uk

Ulster Cancer Foundation
(www.ulstercancer.org)
40-42 Eglantine Avenue

BT9 6DX Belfast, Northern Ireland
Tel:+44 2890 66 3281
Fax:+44 2890 66 0081
E-mail: ucfinfo@ulstercancer.org

8.2 Appendix 2- National Cancer Research Centers

Belgium	Institut Jules Bordet, Centre des Tumeurs de l'Universite libre de Bruxelles	http://www.bordet.be
France	**Institut National Du Cancer**	http://www.e-cancer.fr/
	Instutut Gustave Roussy	http://www.igr.fr
	Instutut Curie	http://www.curie.fr
Germany	**Deutsches Krebsforschungsinstitut**	http://www.dkfz.de/
Greece	'Metaxa' Cancer Hospital Of Piraeus	http://www.metaxa-hospital.gr
	Anticancer Oncological Hospital of Athens 'Saint Savvas'	**N/A**
Italy	Centro di Riferimento Oncologico/Istituto Nazionale Tumori – IRCCS	http://www.cro.it
	Istituto Nazionale per lo Studio e la Cura dei Tumori	http://www.istitutotumori.mi.it/
Japan	**National Cancer Center**	http://www.ncc.go.jp/
Netherlands	**Nederlands Kanker Instituut - Antoni van Leeuwenhoek Ziekenhuis**	http://www.nki.nl/
Poland	**Polish Anti-Cancer Institute**	**N/A**
Romania	**N/A**	**N/A**
Spain	Centro Nacional de Investigaciones Oncológicas (Spanish National Cancer Centre)	http://www.cnio.es/es/index.asp
Sweden	Karolinska Institutet	http://ki.se/
Switzerland	**Swiss Institute for Experimental Cancer Research**	http://www.isrec.ch/
United Kingdom	**Cancer Research UK**	http://science.cancerresearchuk.org/

A detailed list of members of the European Cancer Institutes can be found on the Webpage of the Organisation of European Cancer Institutes (OECI):

http://www.oeci-eeig.org/wcm453/index.php?option=com_content&task=section&id=8&Itemid=41.

8.3 Appendix 3- Important European Societies in Cancer Research

Name of Society or Organisation	Role and Activities

International Agency for the Research on Cancer (IARC) http://www.iarc.fr/	**IARC's mission is to coordinate and conduct research on the causes of human cancer, the mechanisms of carcinogenesis, and to develop scientific strategies for cancer control. The Agency is involved in both epidemiological and laboratory research and disseminates scientific information through publications, meetings, courses, and fellowships.**
Cancer Research UK http://science.cancerresearchuk.org/ http://www.cancerhelp.org.uk/trials/trials/default.asp	**Cancer Research UK is a cancer research and awareness-promotion group in the United Kingdom. It is the foremost cancer charity in the United Kingdom, and the biggest cancer research organisation outside the USA. It is accredited by the UK's National Health Service as a health information provider.** **Cancer Research UK supports and undertakes cancer research in hospitals, universities and medical schools throughout the United Kingdom, and disseminates information to the general public and the scientific community through its various websites, as well as its twice-monthly scientific publication, the British Journal of Cancer. It also makes information about current clinical trials accessible via its website; as at January 2006, there were 211 such trials open to UK cancer patients.**
European Association for Cancer Research (EACR) http://www.eacr.org/about.html	**The EACR was established in 1968 and the membership now exceeds 5000. The Association offers opportunities for:** **Communication** ○ **with laboratory, translational and clinical cancer researchers in all areas of oncology - from basic research, to prevention, treatment and care** ○ **at meetings and special conferences** ○ **with partner international cancer organizations** ○ **in scientific journal (European Journal of Cancer)** ○ **through the EACR Newsletters**
European Association for Neurooncology (EANO) http://www.eano.de/	**The EANO was finally established as an association in 1994. EANO is cooperating with national groups and stimulating international cooperation in neurooncologic research and clinical training. EANO is also involved in the responsibility for the World Conference of Neurooncology, which was first held in Washington in November 2002**
European Organisation for Research and Treatment of Cancer (EORTC)	**The EORTC is an international non-profit organisation that develops, coordinates and stimulates cancer laboratory and clinical research in Europe. It is located in Woluwe-Saint-Lambert/Sint-**

http://www.eortc.be/	**Lambrechts-Woluwe.**
European Society of Gynaecological Oncology (ESGO) http://www.esgo.org/	**The mission statement of the ESGO are as follows:** ▪ **To create an open European platform of individual professionals dedicated to the care of women with gynaecological cancer.** ▪ **To be the authority responsible for recognition of Gynaecological Oncology in Europe.** ▪ **To lead Europe in clinical and scientific education in Gynaecological Oncology and provide standards and supervision for certified training.** ▪ **To independently set multi-professional Standards of Care for women with gynaecological cancer.** ▪ **To integrate clinical and basic research into the educational, training and collaborative activities of the society.** ▪ **To promote communication with scientific and professional organisations within Europe and worldwide.**
European Society for Medical Oncology (ESMO) http://www.esmo.org/	**The ESMO is a professional organization representing medical oncologists. The Society focuses on a multidisciplinary approach to treatment and has expanded to include radiation and surgical oncologists, as well as other healthcare professionals involved in clinical cancer care. ESMO aims to unite physicians, caregivers, and patients in a global alliance committed to combating cancer and ensuring equal access to quality multidisciplinary treatment.** **ESMO strives to certify and maintain the highest standards of overall care for cancer patients by:** ▪ **gathering and disseminating oncology research results** ▪ **supporting oncologists and cancer patients with guidelines, policies and publications** ▪ **offering and accrediting state-of-the-art education and training programs and designated cancer centers**
European Society of Surgical Oncology (ESSO) http://www.esso-surgeonline.be/	**The ESSO was founded in 1981 to advance the art, science and practice of surgery for the treatment of cancer. By arranging scientific conferences, professional exchanges and seminars, ESSO endeavours to ensure that the highest possible standard of surgical treatment is available to cancer patients throughout Europe. It aims to foster multi-disciplinary collaboration in the clinical management**

	of cancer patients. **ESSO is increasingly involved in the training of surgeons concerned by cancer care throughout Europe and in promoting the development of guidelines of good practice in cancer surgery. The Society also seeks to promote knowledge and education about cancer care and to facilitate basic and clinical research in oncology.**
European Society for Therapeutic Radiology (ESTRO) http://www.estro.be/	**The ESTRO was founded in Milano in September 1980. as a Society of individual members working in the field of radiotherapy and oncology. Its principal objectives are to:** ▪ **Foster radiation oncology in all its aspects** ▪ **Develop standards for the quality assurance. of radiation oncology, radiophysics, radiation technology and radiobiology in Europe and stimulate their implementation** ▪ **Improve the standards of cancer treatment by establishing radiation oncology as a clinical specialty integrated with other cancer treatment modalities** ▪ **Promote international exchange of scientific information on radiotherapy & oncology and related fields of science such as radiophysics and radiobiology** ▪ **Set standards for education and practice in radiation oncology and associated professions** ▪ **Establish relationships and cooperation with international, regional and national societies and bodies in the field of radiation oncology.**
Federation of European Cancer Societies (FECS) http://www.fecs.be/emc.asp	**The FECS is the unique umbrella organisation gathering all the disciplines involved in research and treatment of cancer. This society is an international non-profit association that co-ordinates collaboration between European societies active in different fields of cancer research, prevention and treatment with the ultimate goal of providing the best possible treatment and care for all European cancer patients.** **Through its membership, FECS represents more than 18.000 experts involved in cancer research, treatment and care.**
International Agency for Research on Cancer (IARC)	**The IARC is an intergovernmental agency forming part of the World Health Organisation of the United Nations. Its main offices are in Lyon, France. Its role is to conduct and coordinate research into the causes of cancer. It also conducts epidemiological**

http://www.iarc.fr/	**studies into the occurrence of cancer worldwide.**
International Society of Paediatric Oncology (SIOP) http://www.siop.nl/	The SIOP is the major global organisation concerned with the issues of children and young people who have cancer. For the past 35 years it has brought together doctors of many different disciplines to develop better care for this disease.
International Union Against Cancer (UICC) http://www.uicc.org/	**As the world's largest independent, non-profit, non-governmental association of cancer-fighting organisations, UICC is a catalyst for responsible dialogue and collective action. UICC brings together a wide range of organisations, including voluntary cancer societies, research and treatment centres, public health authorities, patient support networks and advocacy groups.** **UICC's mission is to build and lead the global cancer control community engaged in sharing and exchanging cancer control knowledge and competence equitably, transferring scientific findings to clinical settings, systematically reducing and eventually eliminating disparities in prevention, early detection, treatment and care of cancers, and delivering the best possible care to all cancer patients.**
Ludwig Institute for Cancer Research (LICR) http://www.licr.org/	**The LICR is a global non-profit medical research institute that undertakes laboratory and clinical research into cancer, conducting and sponsoring its own early-phase clinical trials to investigate its discoveries.** **LICR is the largest international academic institute dedicated to understanding and controlling cancer, with ~900 staff in seven countries across Australia, Europe, and North and South America. There are currently nine LICR research Branches, which have a primary focus on basic laboratory and translational (in vivo and preclinical analyses of laboratory discoveries) sciences and are typically located within a university or research institute:** ○ **Brussels Branch of Human Cancer Cell Genetics** ○ **Lausanne Branch of Immunology** ○ **University College London Branch of Cell and Molecular Biology** ○ **Melbourne Branch of Tumour Biology** ○ **New York Branch of Human Cancer Immunology** ○ **San Diego Branch of Cancer Genetics** ○ **São Paulo Branch of Cancer Biology and Epidemiology** ○ **Stockholm Branch of Molecular and Cell Biology** ○ **Uppsala Branch of Growth Regulation**

8.4 Appendix 4: Magazines for specific public

Medical Magazines:

- American Journal of Human Genetics
- Annual review of biomedical engineering
- Bioinformatics
- Blood
- Cancer
- Cancer Research
- Computer methods in biomechanics and biomedical engineering
- European Journal of Cancer
- European Journal of Human Genetics
- International Journal of Medical Informatics
- International Journal of Biomedical Informatics
- Internet journal of medical simulation
- Journal of biomedical science
- Journal of Clinical Oncology (Official Journal of American Society of Clinical Oncology)
- Lancet Oncology
- Medical and biological engineering and computing
- Nature
- Nature Cell Biology
- Nature Medicine
- Nature Reviews Cancer
- Nature Reviews Genetics

- Nature Reviews Molecular Cell Biology
- Paediatrics
- Pediatric Blood and Cancer (official Journal of the SIOP)
- Pediatric Hematology and Oncology
- Science
- The Journal of Computational Biology
- The Journal of Medical Internet Research
- The Journal of Pediatrics
- The Lancet
- The New England Journal of Medicine

Legal Magazines:

- Biomedical safety and standards
- Medical law review
- Medical verdicts and law weekly
- The Journal of Healthcare Information Management

Technological magazines:

- Biomedical safety and standards
- Bio-medical materials and engineering
- Frontiers of medical and biological engineering
- Internet journal of medical simulation and technology
- IEEE Trans Biomedical Engineering
- IEEE Trans on Information Theory
- IEEE Trans on Knowledge & Data Engineering
- IEEE Transactions Medical Imaging
- IEEE Transactions on Information Technology in Biomedicine
- IEEE Transactions Pattern Analysis & Machine Intelligence
- International Journal Medical Image Analysis

- International Journal of Grid Computing
- International Journal of Grid Computing & Software Practice & Experience
- Journal of medical engineering and technology
- Methods of Information in Medicine
- Studies of Health Technology and Informatics

8.5 Appendix 5: Magazines for the general public

- Ca m'intéresse
- Science et avenir
- La recherche
- Sciencemag
- Popular science http://www.popsci.com/popsci/
- Science daily http://www.sciencedaily.com/