P-MEDICINE NEWSLETTER

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eHealth
Better Healthcare for Europe

Contents

Editorial

by Norbert Graf, p-medicine coordinator

We are now at the end of the third year of the p-medicine project. A lot of work has already been done by all of us. All milestones set have been achieved so far and we are confident that our ambitious goal of 'paving the way to personalized medicine' will be reached at the end of the project. I am very glad to see that we have been able to build a genuine team over the last three years focusing on delivering the benefits of personalized medicine to patients by creating an IT infrastructure, a legal and ethical framework, tools and services that are driven by clinical needs. As medicine is currently undergoing a huge change by focusing on integrated diagnosis, treatment and prevention of disease in individual patients, personalized medicine is today's greatest challenge. It needs to deliver individualized medicine at the right time to the right patient. The promising results of this are measurable improvements in outcomes and a reduction of health care costs.

One part of this newsletter has its focus on the security framework, giving an overview of the Center for Data Protection (CDP) and showing how data sharing is handled to be in compliance with legal requirements. This framework can serve as a model for other projects where sharing of clinical data is essential. It is a real step forward and already under discussion in other European projects like ENCCA. The implementation of security tools in ObTiMA and the p-medicine data warehouse will enhance the collection of clinical and research data for the scientific community. It is not only because of this legal framework that p-medicine is increasingly recognized in the scientific community through its biobanking module "ObTiMA" and the p-BioSPRE (p-medicine Biomaterial Search & Project Request Engine) framework.

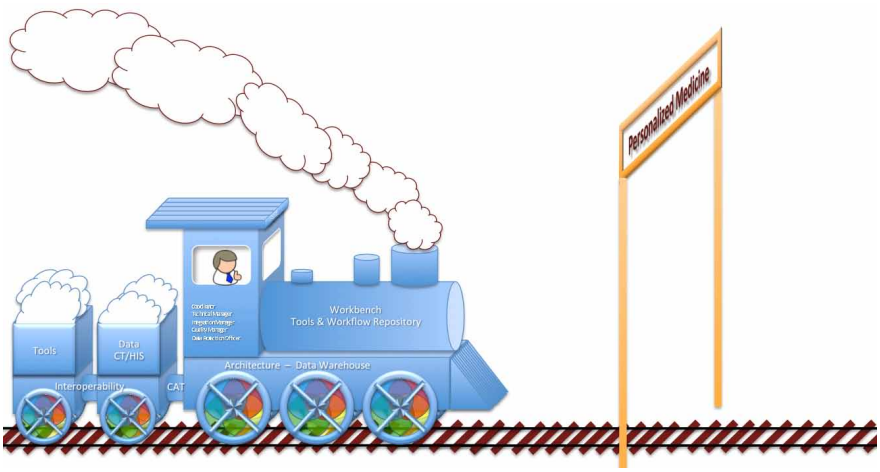
The legal framework represents only one important aspect of the project. There are others, like patient empowerment tools, the p-medicine portal, the data warehouse, the biobank access framework, decision support services, the Oncosimulator, sematic interoperability and usability issues regarding IT-tools and services, which have been described by groups of highly experienced researchers from different disciplines for a special issue on p-medicine to be published by p-medicine partner ecancer soon. They show perfectly the integrated approach of the project. The goal of personalized medicine can only be reached successfully by a team of different stakeholders who all focus on the same topic.

Networking is very important and it did not only take place during our successful 2nd Summer School in Computational Oncology at Schloss Dagstuhl in June 2013 in which scientists from other European projects as well as from outside the community participated. Several specific meetings with European projects allowed intensive discussions enhancing close collaborations, e.g., with VPH-Share, ENCCA, CHIC, EURECA, MyHealthAvatar and others.

The most important question that the p-medicine consortium will have to face in its last year of the project concerns sustainability and maintenance of the project beyond the funding period. The funding of STaRC (Study, Trial and Research Center) as a legal entity is fostered as one possibility to guarantee the sustainability of the project's results. In addition, we are keeping an eye out for options in Horizon 2020 to further proceed with our ambition of a personalized medicine for all patients.

I am very honoured to coordinate such an ambitious project with wonderful and productive partners and, if I might even say, friends. Their tremendous work, interfacing and collaboration form the basis for our success. Thus our 'p-medicine train' keeps on running reaching one milestone after the other...

Norbert Graf
p-medicine coordinator



Towards a personalized medicine

The Cat Platform

Many people involved in clinical research in Europe not only think of cute furry animals when they hear the word CAT, they also know it to be a means to conveniently anonymise clinical data so that it can be shared and used in collaborations.

CAT (Custodix Anonymisation Tool) started out years ago as a standalone tool for manual de-identification of datasets and has since grown to be a versatile service platform which can be easily integrated into high volume data workflows for de-identification of all types of data. The operating principles behind the tool have, however, remained the same.

Protecting the privacy of patients listed in research databases is a complex task. Most people are aware of the fact that it is certainly not sufficient to remove obvious identifiers from a dataset to de-identify it. Adequate privacy protection involves thorough risk assessment in order to define how the data must be transformed (e.g. through perturbation, suppression, aggregation, etc.) to guarantee that data cannot be re-identified. This is largely a manual task. However, once data protection experts have determined how data is to be transformed to achieve compliance, treating the data can be handled by the CAT platform without much effort. All that needs to be done is to map the input data to a generic data model and define a "privacy profile" which specifies how data is to be processed.

Privacy profiles determine the actions that need to be performed on data to render it anonymous (or pseudonymous). They contain instructions such as:

- Remove all patient names
- Calculate a pseudo-ID based on a patient-ID
- Make all patient visit-dates relative to the patient date of birth and randomise that date
- Process all free text to remove identifying information
- Etc.

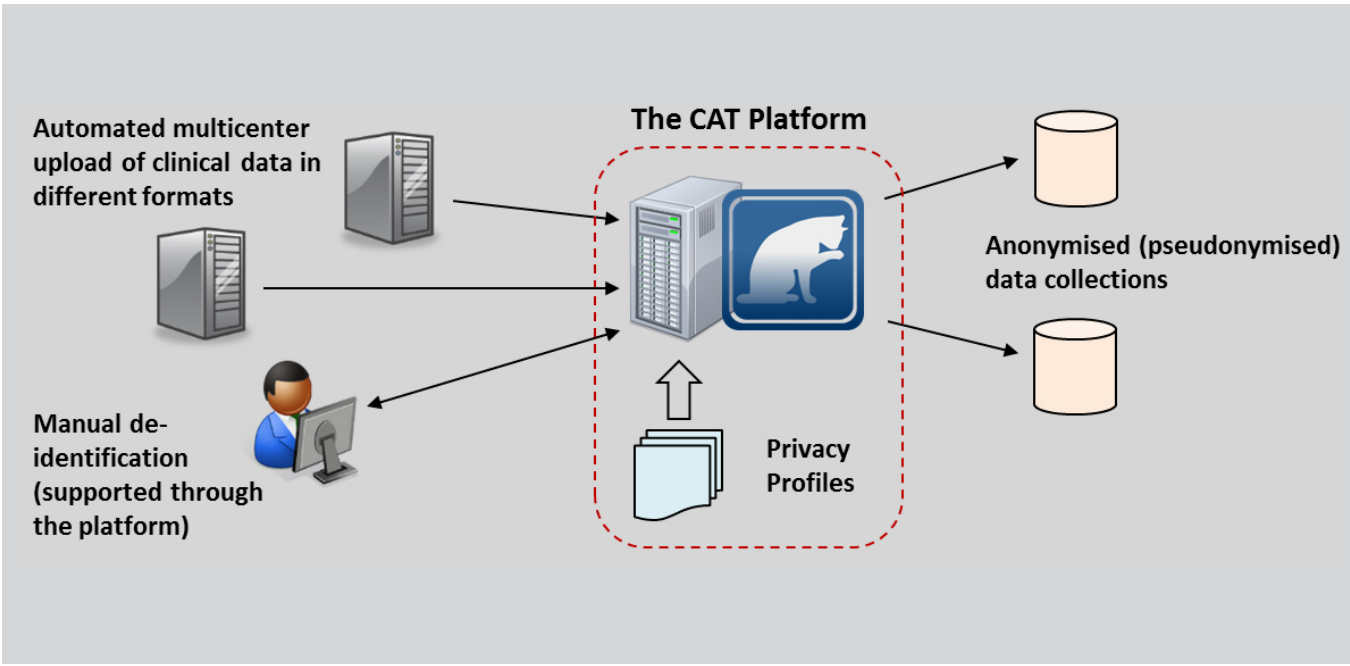
This two-step approach (data mapping and the use of privacy profiles) allows for uniform processing (i.e. with the same privacy profile) of data in different formats. It is not only more convenient for setting up a project, it also provides a higher assurance level with respect to compliance.

CATS
Custodix Anonymisation Services

The CAT platform currently supports processing data in the following formats: CSV ("Comma Separated Values"), XML, HL7, DICOM, microarray data and is capable of performing operations on relational databases directly through SQL. Due to the modular design, end-users can add modules that support their own proprietary data formats.

The CAT platform has been used in many clinical data sharing projects all over Europe inside and outside of the context of EU IST projects. The p-medicine project also relies on the CAT platform to make anonymised data available to its researchers.

More information



Partners in Depth: CUSTODIX

Custodix is a Belgian SME that offers a wide range of IT tools and services for securing sensitive data and protecting privacy. Custodix is primarily active in the health and life sciences domain, where it acts as Trusted Third Party (TTP) ensuring compliance during data collection, sharing and processing. Custodix' product portfolio includes various tools for data de-identification (anonymisation and pseudonymisation), encrypted storage and an Identity and Access Management suite (CIAM).

The company consists of a highly skilled and experienced team capable of dealing with all IT aspects related to environments requiring adherence to the highest security and privacy standards, including: setup, hosting and management of high security IT environments, system architecture and integration (application security focus) and custom IT development.

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Short CV Elias Neri

Elias Neri holds a master degree in software development. He has participated in several European (IST) research projects in which his focus has been on security and data protection related research topics. Elias is an IT researcher with expert knowledge of the Java programming environment and has as such been responsible for much of the prototyping of Custodix' tools.

Elias is leading the Custodix team working in p-medicine.

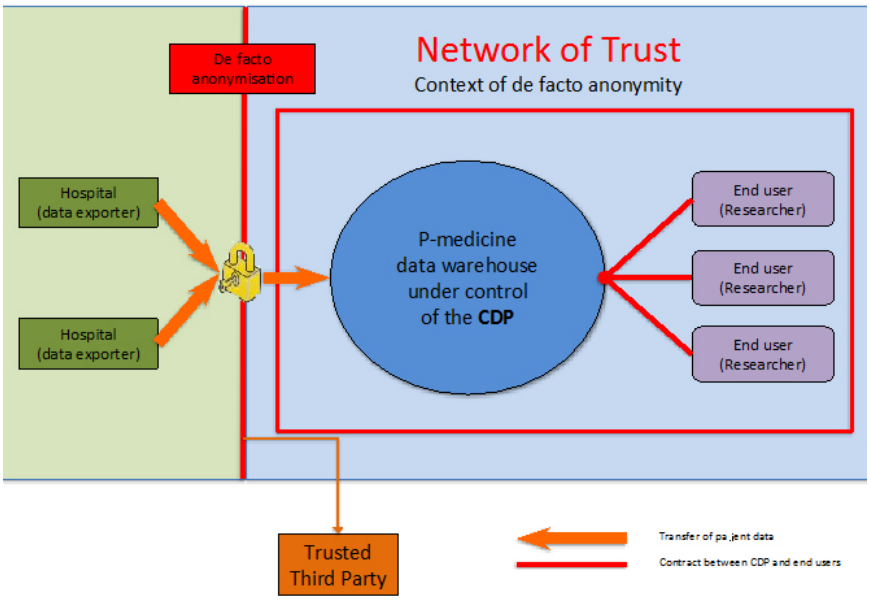
Short CV Brecht Claerhout

Brecht Claerhout holds a master degree in electronics engineering. He was previously active in FOSS development as author of a major network security tool (Sniffit) and worked at the IMEC (Interuniversity Microelectronics Center) and RAMIT (Research in Advanced Medical Informatics and Telematics) research groups. Being employed at Custodix for over a decade he has been actively involved in a large number of European research projects mainly dealing with health data integration. He has published several conference and journal papers on the subject of security and privacy protection and semantic integration of clinical data.

Brecht is currently CEO of Custodix.

The Center for Data Protection (CDP) and its Role in p-medicine

The Center for Data Protection (CDP) is a spin-off from the EU FP6 „Advancing Clinico-Genomic Trials on Cancer“ (ACGT) research project in which an international biomedical research network was established. Founded in 2007, CDP is a non-profit organization registered under Belgian law and dedicated to providing support to the European biomedical research community on issues of data protection. Having successfully contributed in the data management of the ACGT project, the CDP is currently supporting the p-medicine project with its multidisciplinary expertise in data protection and data security.



In p-medicine, the data protection and data security framework that has been developed to securely share patient data in compliance with applicable data protection laws benefits from the CDP's data management tools and infrastructure. Core of this legal framework is the concept of "de-facto" anonymity of data, which is facilitated by a second pseudonymization of data before they are stored in a central data warehouse developed for the project. While the first step of pseudonymization is carried out by the hospital providing the research data, the second is performed by a Trusted Third Party (TTP) that works in collaboration with the CDP. The use of the TTP here is to ensure that the pseudonymization key is more securely managed, and also to achieve a functional separation of roles between technical and administrative measures in the research data management.

In addition to the technical measures, p-medicine has developed a contractual framework. Basically acting as a "data protection authority" for the consortium, the CDP concludes contracts with all research partners that will have access to data, in which obligations for data confidentiality have been included. Furthermore, the CDP is responsible for data processing within the data warehouse and ensures compliance with the data protection and data security policies set up for the project. As part of the policy, re-identification of patient data is, in principle, forbidden, except where a treatment has been found that could be beneficial for a patient, and that patient has given his informed consent to re-identify him in such a case. This procedure appears ethically desirable. However, to ensure that re-identification will happen only in such a case, a clearly defined procedure must be adhered to. Re-identification in this case follows four steps: In the first step, a researcher has to address the CDP and explain the reasons for the request to re-identify the patient concerned. It has to be shown that re-identification is clinically beneficial and ethically appropriate for the patient. When this requirement is fulfilled, the CDP will send a request to the TTP regarding the key to the patient pseudonym. In the third step, the TTP will transmit the original pseudonym received from the hospital when the data was transferred to the p-medicine data warehouse to the hospital where the patient was treated. Finally, the hospital will inform the patient about the new developments that could be beneficial for his treatment. In no case shall a researcher directly address the patient.

The diagram above shows the central role of the CDP as a conduit pipe that facilitates the interaction between hospitals and researchers for the use of data in a secure manner.

As a further responsibility in the p-medicine project, the CDP has taken on the role of a central contact point for patients regarding all data processed within the p-medicine infrastructure, including data processed under the control of the end users.

Having the necessary knowledge and experience with the complex European data protection and data security regime, the CDP relieves all parties from a huge burden which allows them to concentrate on their primary objective – the research and the good of humanity.

Center for Data Protection
CDP
www.privacypeople.org

More Information

Short CV Prof. Dr Nikolaus Forgó

Nikolaus Forgó, born in 1968 in Vienna (Austria), studied law, philosophy and linguistics in Vienna and Paris. In 1997 he received a doctorate for a dissertation on legal theory. From 1990–2000 he worked as an assistant at the law school of the University of Vienna and was inter alia responsible for the ICT-infrastructure there. In 1998 he founded a postgraduate program on ICT-law in Vienna and has been the head of this program since then.

In 2002 Nikolaus Forgó became Professor of Law at the Institute for Legal Informatics at Leibniz University Hannover in Germany *(www.iri.uni-hannover.de)*. For seven years he has been head of the institute and responsible for the supplementary course in computer science law.

Since 2012 he is also a honorary professor at the University of Vienna and a member of the L3S Research Center of Leibniz University Hannover. He is also president of the Center for Data Protection (CDP), a non-profit organization that was founded in August 2007 as a spin-off from the European research project „Advancing Clinico-Genomic Trials on Cancer" (ACGT).

Under his direction the Institute for Legal Informatics is involved in various research projects with a wide range of subject matters, such as information systems in personnel, telecommuting, data protection law, international data traffic, medical law and medical ethics. A number of projects deal with the development of e-health (e.g., p-medicine, EURECA, PONTE, Linked2Safety). The institute's expertise lies on the consultation of project partners and research in legal and ethical matters, especially in data protection and intellectual property issues.

Special issue on p-medicine published by ecancer

In February 2014, a special issue on p-medicine was published by ecancer. It includes five articles and relating interviews by different consortium members. In addition to an editorial on the various aspects of the p-medicine project, the special issue includes the following four articles:

- An article on p-BioSPRE, an information and communication technology framework for transnational biomaterial sharing and access
- Development of interactive empowerment services in support of personalised medicine
- Usability on the p-medicine infrastructure: an extended usability concept
- The p-medicine portal – a collaboration platform for research in personalised medicine

You can read the articles here: *http://ecancer.org/special-issues/3-the-personalised-medicine-project.php*

Health Data Ontology Trunk (HDOT)

The Health Data Ontology Trunk (HDOT) constitutes the semantic framework of p-medicine. It provides formal representations of terms and expressions, and relates them to each other within a single ontological structure. The semantic content relevant for this purpose comprises heterogeneous kinds of information that are required for making high-quality standardized metadata available, e.g. for data annotations. These metadata are necessary for describing the meaning of data handled in the project in an unambiguous and coherent way.

HDOT contains machine-readable formal specifications of concepts that are correlated to terms and expressions and thus teaches computers some key elements of the meaning of semantic representations that biomedical professionals use to describe their subject matter. It is obvious that these representations need to be standardized to a very high degree and that their appropriateness and ontological quality have to be carefully assessed and maintained. We have therefore decided to avoid new semantic representations whenever possible and to rely on pre-existing, well-established semantic resources (SRs) instead, from which we re-use relevant parts and re-arrange them into a new structure that can accommodate the requirements of the project.

This new structure captured in HDOT sets our approach apart from most of the semantic solutions in other projects which often make different pre-existing ontologies available for data description, but very rarely bring their contents together under one unified semantic framework in which their concepts are related to each other.

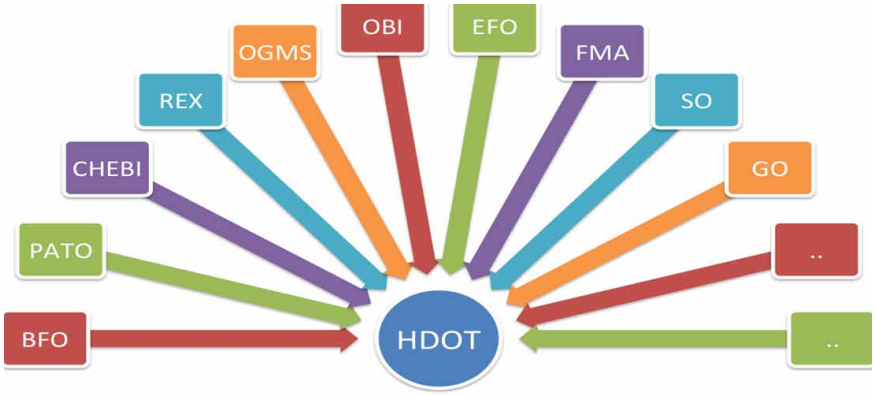
We defined a set of quality and appropriateness criteria for evaluating SRs which are computer processable and use these to evaluate which parts of the SRs can be re-used. We pay particular attention to the availability of natural language definitions of concepts for two reasons.

First, natural language definitions can help users in deciding whether a concept in an SR is a good representation of what they have in mind or not.

Second, we can exploit them in order to make the starting points more transparent from which more formal axiomatisations of concepts are developed. Regarding the knowledge and capabilities of HDOT's users we made as few assumptions as possible.

We would like to point out that we did not expect or even attempt to capture and cover all required concepts or terms in HDOT. Indeed, p-medicine's field of inquiry is far too dynamic and progress in it far too rapid. That is why we have designed HDOT as a flexible modular middle-layer ontology. Its concepts are general enough that meaningful subsumptions of more specific concepts are always possible and specific enough that these subsumptions always add meaningful constrains to a concept. Its concepts thus feature a certain middle level of generality. More detailed concepts are then added in modules that specialize particular areas to the desired degree. The curators have already provided some core modules for very important fields in the project such as pathological formations, patient empowerment or biobank material.

These modules can be switched on or off so that users are able to only access those parts of HDOT which are relevant for them. At the same time, this ensures that the project's semantic framework is flexible enough to be adapted easily to ever changing needs and unforeseen requirements because adaptions can be localized in one module without affecting others. We can further associate a module with a user and let them compile their own dedicated semantic representations in the form of a new or adapted module within this framework by using our semi-automatic Ontology Aggregator Tool (OAT). This tool provides access to more than 350 SRs stored in the National Centre for Biomedical Ontology's BioPortal and allows the re-use and integration of parts (single concepts or even whole branches) of them as HDOT extensions. These new HDOT modules are generated on-the-fly so that a user can continue working with them straight away.



Parts from other ontologies re-arranged into HDOT

CONTACT

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Enabling Full Semantic Database Integration in p-medicine

During the last year, p-medicine partner *UPM (Universidad Politécnica de Madrid)* has focused its efforts on the finalization of all core features of the Ontology Annotator. As a result, the first production version of this tool has been launched/produced/generated, allowing the effective annotation of biomedical data sources for their automatic integration in the p-medicine platform. The development of the Ontology Annotator and its related technologies has been accompanied by an effort to disseminate the achieved results. So far, the tool has been featured in a poster in the Medinfo 2013 conference, and the underlying approach is expected to be soon published in a special issue of the Methods of Information in Medicine journal.

Future efforts will focus on validating the Ontology Annotator with real-world scenarios, and producing quality documentation and tutorials targeted at end users.

Fostering usability

Throughout the past year, efforts have focused on assessing and improving the usability of the Ontology Annotator. To do so, UPM has closely collaborated with SIB (Swiss Institute of Bioinformatics) in order to perform usability tests with end users. The results of these tests have allowed improving several aspects of the interface and the existing tool tutorials. Work on this area will continue in 2014, with the participation in a usability workshop organized by ecancer in Hannover in April, as well as the development of a module for guiding non-expert users in the annotation process. Scalability is another aspect being worked on, as part of the scalability and performance strategy of the p-medicine platform. At this point, an analysis of the tool performance has been completed, and there is an initial plan for improving the responsiveness of the tool in the most common tasks. There is a big challenge ahead, due to the complexity of handling large repositories of data in an efficient and effective manner.

Connection and integration with other tools

The Ontology Annotator is currently undergoing the last steps in the integration with the Data Warehouse. UPM collaborates with UCL (University College London) in conducting joined tests to guarantee proper data coherence and full compliance of the integrated sources with the HDOT ontology.

In addition, the Ontology Annotator now provides direct access to the first version of the Ontology Aggregator tool, developed jointly by USAAR-IFOMIS (the Institute for Formal Ontology and Medical Information Science of Saarland University) and UPM. This tool enables users to autonomously extend HDOT with new terms, increasing the scope of the ontology adopted by p-medicine to represent the integrated data. Further integration efforts will be carried out during 2014 to make the Ontology Annotator fully aware of the dynamic changes performed over HDOT by end users.

Integration of public data

Upcoming efforts will focus on exploiting the Ontology Annotator by bringing public repositories to the p-medicine platform. In this sense, the UPM team will take advantage of its previous work on building RDF wrappers of the NCBI database set to integrate these repositories with the rest of the clinical data stored at the Data Warehouse. The Ontology Annotator will allow the automatic translation of the high volumes of data provided by the NCBI. This feature is expected to provide an increased value to the p-medicine platform, by enabling more productive knowledge discovery processes.

More information

Ampoule-PI: A Flexible Warehousing Tool for Health Informatics Data

Health informatics relies, in part, upon computational simulation, modelling and data mining methods. These, in turn, rely upon information from multiple sources, which is currently organised without reference to universal standards of terminology, language or schema. The p-medicine data warehouse is a repository for securely storing and maintaining data from diverse sources integrated semantically to enable reporting and analysis. It is not typically intended to be used as a live data store. Live data stores often purge old data which may be useful for analysis, and they need to support operational systems which have different quality of service needs.

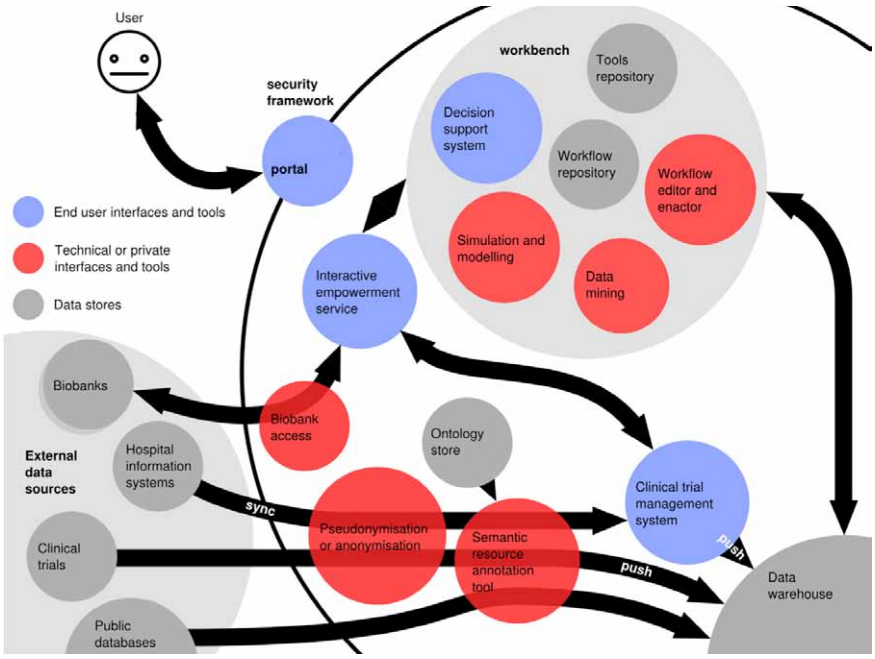
We are presented with the challenge of taking heterogeneous data from multiple sources, and presenting it in a consistent and standardised manner to predictive computational tools. The ampoule-pi data warehouse is an open source/open standards based tool designed to do this. The warehouse is able to ingest any kind of data type and build a triples store merging the information of all of them, presenting a novel structure for the warehouse.

Key features

Federation: Multiple data warehouses can be linked into a federated network. Queries to a particular warehouse can be delegated to others, and results collated and returned, or structured data can be replicated in multiple data stores for faster query response.

Tools: Data mining and modelling tools benefit from a consistent data model which is centrally maintained, curated and is secure. They can also use the data warehouse to store intermediate and output data.

The warehouse is structured around four layers. The human web interface enables browsing by modellers and data curation, and RESTful (Representational State Transfer) programmatic interfaces are exposed for data access by domain-specific tools. Standard data access functions are provided. Query of structured data is via SPARQL (SPARQL Protocol and RDF Query Language). Access to files is via standard protocols, and image access is via the DICOM (Digital Imaging and Communications in Medicine) protocol enabling HIS (Host Integration Server) integration.



The integration layer ensures data linkage, quality and auditability. Logging keeps track of access and edits, History keeps historical values, Curation provides data annotation, and Provenance keeps track of sources for data. Semantic integration is provided via additional tools.

Storage of the underlying data can be distributed and provided by arbitrary suppliers, via local or cloud based storage resources. Storage is based on existing file, image and triplestore (structured data) servers which are integrated with authentication and authorisation services.

Modules

The data warehouse needs also several modules attached to it in order to make it functional and secure.

The data annotation tool task consists in the semantic alignment of databases with *HDOT (Health Data Ontology Trunk)*. This tool is aimed at end-user clinicians and/or database administrators who must have some comprehension of basic database concepts, but do not necessarily have expertise in the RDF paradigm.

The uploader module exports the data from their primary sources, adapts the data to a supported format, applies an anonymisation to this data, and stores the annotated data in the data warehouse.

Finally, the last module is an ontology-based clinical trial management system intended to support clinicians in both designing and conducting clinical trials in a user-friendly way.

All communications between these modules have to be embedded in a secure framework managing all users working in the system and avoiding non-allowed access to it.

More Information

Dealing with the Data Glut in Healthcare

by Edwin Morley-Fletcher

With the ever-increasing volumes of data being produced outstripping (For instance, in genetics DNA gene sequencing machines based on Big Data analytics can now read 26 billion characters of the human genome in seconds), and arguably being driven by, the computing power available to analyse them (quantum computing aside possibly), we already are faced with the reality that we have too much data.

As of 2011, this "data glut" was estimated to be 150 exabytes (150 billion gigabytes) for healthcare globally. To make sense of so much data, where sense is to be found, will require innovative analytical techniques that can make it possible to efficiently search, process and analyse these massive datasets. Some handle may be gained over the torrent of data by reducing the dimensionality of a dataset. Feature selection methods, whether selecting features on the basis of existing medical knowledge or on statistical techniques, can be used to map a dataset with many feature dimensions to one with significantly fewer, thus creating a manageable search space. This simpler search space is then used for querying and analysis, with the full dataset only referred to when necessary, allowing for the application of goal-oriented search techniques such as Model-Driven Analysis. Fractional Factorial Design uses this sort of approach to concentrate search efforts in areas of a multi-dimensional dataset that have been selected by searching a lower-dimensional one that it has been mapped to.

These and other techniques allow us to find correlations, patterns and structures in overwhelming volumes of data, giving them value. They reinforce the fact that **data do not possess inherent value in the absence of a means to make sense of them.** They are meaningless until analysed for significance, visualised within a context or compared to other data. This means that the value of a dataset will vary according to its context. The corollary of this is that the value of a dataset is the sum of its values in each analytical context. This fits neatly with the concept that it is the research results, services and products generated from data that will provide the value in a Big Data economy.

The value of bio-medical Big Data repositories

Given the fact that data are "experience goods", according to Arrow's paradox it should be true that once access to them has been awarded, their value should be significantly reduced because of the inherent non-rivalry and non-excludability characteristics of open access information. However, Big Data repositories coupled with analytics can be utilised in a variety of excludable ways and their value is not critically influenced by Arrow's paradox, while the "experience goods" challenge mainly concerns the availability of "enough" descriptive information about the data, their structure, process of collection, and possibly "teasers" about the analyses or outputs from the database.
However, it remains true – as stated in the OECD Report on "Supporting Investment in Knowledge Capital, Growth and Innovation" – that in order to reap this growing value there will be the need not only for clinicians and researchers to acquire Big Data analytics skills and services, but also to develop a framework for data repositories which adheres to international standards for the preservation of data, sets common storage protocols and metadata, protects the integrity of data, establishes rules for different levels of access and defines common rules that facilitate the combining of datasets and improve interoperability. These frameworks could, someday, render some of today's data protection rules and procedures invalid.

The goals here are:

- to be able to provide model-driven patient-specific predictions and simulations and consequent optimised personalised clinical workflows,
- to allow for advanced similarity search among patients, such that clinicians can find "the patient like mine", and
- to get support through risk stratification and outcome analysis.

Eventually it is hoped that specific pathophysiological patterns ("disease signatures") can be detected, refined and made available to other clinicians and researchers in the form of pattern libraries.

These pattern libraries, identifying homogenous groupings among patients and model similarities, could be shared between researchers and clinicians to allow for data intensive pathophysiological diagnoses. Allied to the above is the potential to revolutionise health communications by making it possible, on the basis of semantically advanced repositories, to use social media among patients aware of sharing highly similar conditions ("patients exactly like us"), empowering them to bridge the gap with the clinicians, especially in the case of paediatric patients and their parents.

This document is an extract of a discussion paper produced for the Networking Session on "Big data and data analytics impact in healthcare" organised by the FP7 integrated project MD-Paedigree, partially funded by the European Commission, for November 7th, 2013, as part of the ICT'13 conference in Vilnius. Its author is Edwin Morley-Fletcher.

P-MEDICINE – OTHER RELATED PROJECTS AND INITIATIVES

BioMedBridges reaches its half-way point

BioMedBridges is an ambitious project to achieve interoperability of data and services across ten European research infrastructures and the range of different scientific communities they serve. Half way through the project, at the end of year two, this is a great time to celebrate a few of the achievements.

Moving closer to data integration and discovery

Based on the pilot data integration using REST web services and the identification of feasible pilots for semantic web integration between the project partners, a first set of services was developed. These services include:

- a server for secure sharing and integration of medical imaging data (Euro-BioImaging)
- a new, connectivity-based search function for UniChem (EU-OPENSCREEN)
- a method for sharing and visualisation of sequencing data from environmentally-derived biological samples (an in-kind contribution from EMBRC in collaboration with the Micro B3 project)
- a tool for the visualisation and leveraging of ontologies in queries (Euro-BioImaging)
- a tool for the integration of gene and drug information with a clinical trials registry (ECRIN)

A legally and ethically sound basis for data sharing

The basis for work with ethically sensitive data within the project is provided by the BioMedBridges Ethical Governance Framework. Even more importantly, the efforts of the „Secure access" work package of BioMedBridges during the first half of the project were also focused on ethical and legal aspects of sharing data that underlie certain restrictions, such as personally identifiable information or intellectual property.

The tool, which provides background information as well as contractual templates (e.g. data transfer agreements and consent forms) will provide working scientists with significant support in the navigation of the complex regulatory landscape.

More news on BioMedBridges are available in the project's newsletter. Subscription is possible on *www.biomedbridges.eu*.

VPH-Share: Refining the Infrastructure and Calling New Users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In September 2013 the project made available its workflow composition tool, which allows users to construct workflows directly on the VPH-Share portal. With an easy drag and drop approach, users can choose and configure components, define parameters, link input data and control outputs. Juan Arenas, from Sheffield University, who coordinated the tool's development said: "This functionality will facilitate the communication between users as it will remove the need to install any specific software on their computer to compose or run a workflow. We suspect that it will even shorten the validation cycle of new biomedical workflows."

Ongoing work from the Project Management Office has seen the establishment of a group of external use cases, designed to test VPH-Share, both through the validation of existing services and the addition of new data and tools. The group comprises the four flagship workflows, which are now reaching out to new users, the support of 13 existing projects including ARTreat, MySpine and RT3S, the support of a new initiative, vFFR1D and the incorporation of six existing community tools, including BioMedTown and Physiome Space.

Peter Hoskins, from the University of Edinburgh, said: "I am very pleased to be involved with my colleagues in Sheffield and in the VPH-Share programme of work. With Phil White (Prof of Interventional Radiology in Newcastle) we hope to use the VPH-Share funding to perform pilot studies using the Gimias workflow for segmentation and stress analysis in cerebral aneurysms. The pilot data can be used in major clinically led grant applications to better understand the disease process and aid diagnosis and treatment of cerebral aneurysms."

Recent technical milestones include the release of parameter estimation and uncertainty modelling strategies along with markup languages to formally represent uncertainty and parameter estimation. VPH-Share members were also very pleased to contribute to a number of joint papers with p-medicine colleagues, in November 2013, in the Proceedings of the Krakow Grid Conference. On the project's recent developments, Scientific Coordinator Rod Hose said: "I am excited that VPH-Share is entering a phase of strong engagement with internal and external users."

p-medicine members who wish to integrate tools with the VPH-Share infrastructure please contact *Debora Testi.*

A demonstration of the workflow composition tool can be seen *here*.

A Great Success: p-medicine Summer School in Computational Oncology

It was one of the p-medicine highlights in 2013: From June 24-28, 2013, Prof. Graf and his organizing team from p-medicine's management partner Eurice welcomed more than 35 researchers, clinicians, medical and engineering students to the 2nd Summer School in Computational Oncology, the first seminar in clinical medicine held at the renowned Leibniz Center for Informatics at Schloss Dagstuhl in Wadern, Germany.

With its remote location, its state-of-the-art facilities and on-site catering and accommodation, Schloss Dagstuhl provided the ideal location for one week of knowledge exchange and in-depth discussions. The interdisciplinary workshop offered a balanced mix of presentations and application-oriented tool demonstrations. Around 40 internationally renowned pioneers in computer-based cancer research gave lectures on five key aspects in computational oncology: Impact of IT towards personalised medicine, Molecular Biology and Bioinformatics, Law and Ethics in IT frameworks for personalised medicine, Usability, Interoperability and Sustainability. After each lecture, junior and senior researchers from the p-medicine partner projects CHIC, EURECA, INTEGRATE and VPH-Share had the opportunity to present their activities and tools. The one-week workshop thus successfully covered a wide range of multidisciplinary aspects of computational oncology. This included the exchange of views and experiences related to clinical and engineering/basic science gathered in the frame of major European projects in this field.

The overall goal: tailor-made therapies

The first Summer School in Computational Oncology took place in Heraklion, Crete from June 13-18, 2011. It was organised by the p-medicine partner Foundation for Research and Technology Hellas (FORTH).

The idea behind these Summer Schools is to provide students and young researchers from various backgrounds with necessary knowledge and skills required to understand the basics of both the multiscale cancer modeling and the biomedical informatics framework. These are needed to bring computational oncology closer to the clinical setting and decision-making process. The latter forms the basis for achieving the overall goal of p-medicine: To place patients in the centre of interest of medicine and offer tailor-made therapies for as many people as possible.

The 3rd Summer School in Computational Oncology will be held in 2015. It will be organized within the scope of the p-medicine partner project CHIC – "Computational Horizons in Cancer. Developing Meta- and Hyper-Multiscale Models and Repositories for In Silico Oncology."

And...action, please!

On June 25, a professional camera crew filmed lectures and interviews with Prof. Graf and other scientists at the Summer School. These can be seen in the film „*Computer Science Meets Medicine*" about the „STaRC" (Study, Trial and Research Center) project.

Further interviews were filmed by p-medicine partner ecancer. They are available on the *p-medicine website* and on *ecancer.org*.

Advanced IT-support for modern clinical trials

What can EU projects and infrastructures offer?

A two day workshop with presentations and demonstrations to be held on May 26-27, 2014 in Düsseldorf, Germany and organized by ECRIN together with other EU-funded projects (TRANSFoRm, EHR4CR, p-medicine, BioMedBridges and ECRIN-IA)

Aim of the workshop

The workshop will give interested persons an overview on what EU projects and EU infrastructures have developed as software tools or services to improve clinical trials. In breakout sessions, developers will demonstrate their tools and services (e.g. CDMS, biobanking tool, imaging tool, feasibility and recruitment service). The usability, maturity and benefit for clinical trials will be evaluated and discussed.

The targeted audience includes software developers and potential users from EU projects and EU services as well as clinical researchers and trial specialists from academia and industry in charge of planning and performing clinical trials.

European Clinical Research Infrastructures Network

The European Clinical Research Infrastructures Network (ECRIN) has become a sustainable, not-for-profit infrastructure supporting multinational clinical research projects in Europe. ECRIN provides information, consulting and services to investigators and sponsors in the preparation and in the conduct of multinational clinical studies. ECRIN support is particularly relevant for investigator-initiated or small and medium enterprise-sponsored clinical trials. Currently, ECRIN-IA is funding trials in the areas of rare diseases, medical devices, and nutrition.

ECRIN, via its data center certification programme, is promoting the use of high quality data management tools/ services for clinical trials.

Recently a paradigm shift in clinical trials has been noticed: clinical trials are opening up to care data and Big Data. New software applications are being developed that will change the way clinical trials are conducted. In health-care and pharmaceutical research, data growth is generated from many sources, including primary care registries, hospital information systems, electronic health records, mobile tools, and data originating from genomics, epigenomics, proteomics and metabolomics.

Effectively utilizing these data will help researchers to better identify new potential trial participants, enroll them more easily, conduct a trial more efficiently, implement innovative trial concepts based on data from basic and translational research (e.g. personalized medicine) and move new interventions faster into effective and safe therapies.

Contribution of EU-funded projects

Several EU-funded international projects will provide new ways to increase the efficiency of clinical trial conduct and the way data management is done in clinical trials. Their applications will be evaluated and tested in ECRIN and may in future provide a considerable contribution to enable ECRIN to support advanced clinical trials.

a. **TRANSFoRm (EU FP7)** aims to develop the technology that facilitates a learning health care system. Three carefully chosen clinical use cases will drive, evaluate and validate the approach to the ICT challenges of embedding decision support and clinical trial workflow into the EHR and providing a secure infrastructure for large scale genotype-phenotype studies using primary care data.

b. **The EHR4CR (IMI)** project is – to date – one of the largest public-private partnerships aiming at providing adaptable, reusable and scalable solutions (tools and services) for reusing data from Electronic Health Record systems for Clinical Research.

c. **p-medicine (EU FP7)** "From data sharing and integration via VPH models to personalized medicine" is aiming at developing new tools, IT infrastructure and VPH models to accelerate personalized medicine for the

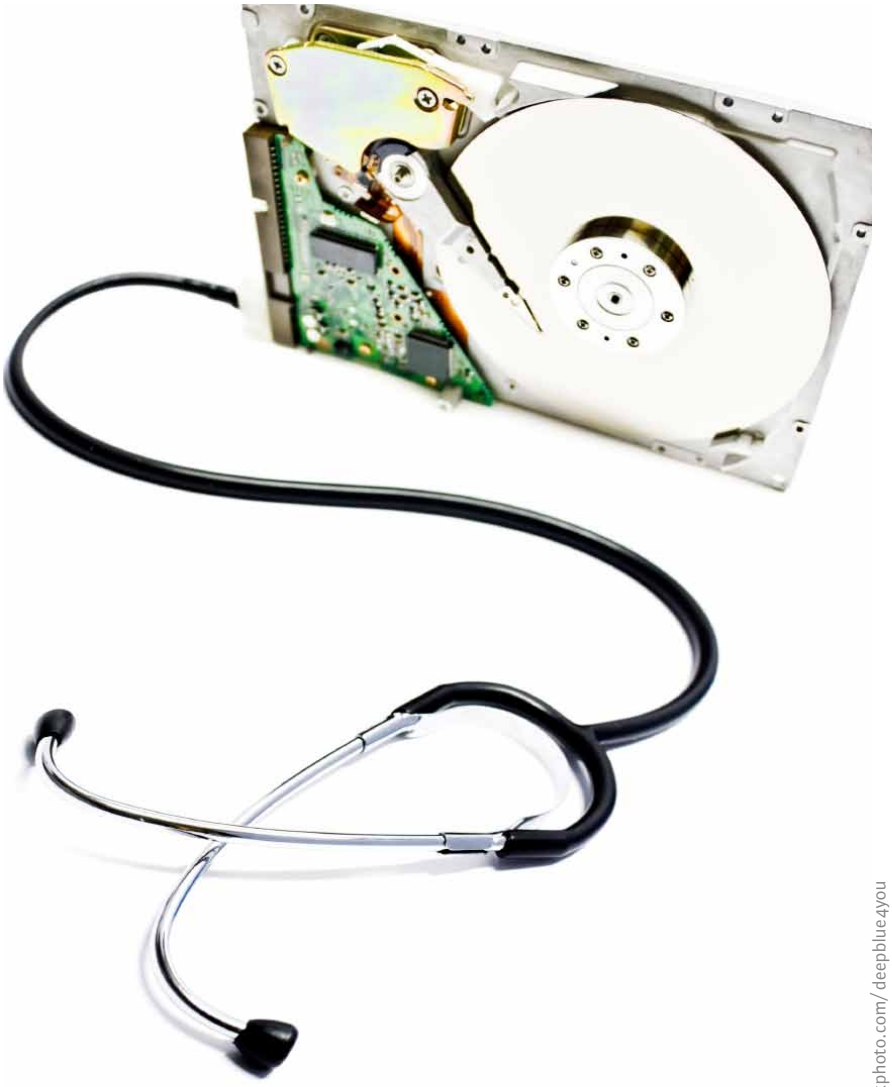
benefit of the patient.

d. **BioMedBridges (EU FP7)** is a joint effort of ten biomedical sciences research infrastructures on the ESFRI roadmap. Together, the project partners will develop the shared e-infrastructure – the technical bridges – to allow interoperability between data and services in the biological, medical, translational and clinical domains (e.g. within the use case of personalized medicine) and thus strengthen biomedical resources in Europe.

e. **ECRIN-IA (EU FP7)** is designed to build a consistent organization for clinical research in Europe, with ECRIN developing generic tools (e.g. the VISTA data management tool) and providing generic services to multinational studies, and supporting the construction of pan-European disease-oriented networks that will in turn act as ECRIN users and provide the scientific content.

f. **There are many more EU projects and EU infrastructures which also contribute to this area and will be invited.**

More information



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Launch of Horizon 2020: First Calls for Projects in 2014/2015 Now Open

The European Commission has presented the first calls for projects under Horizon 2020. Over the first two years the Commission will support research and innovation initiatives with a total funding of more than €15 billion. Horizon 2020 is the biggest EU Research and Innovation Programme ever. Within its lifecycle of seven years (2014-2020) there will be an overall budget of nearly € 80 billion.

The goal of Horizon 2020 is to ensure world-class science in Europe, to boost Europe's knowledge-driven economy and to address major societal challenges such as health, energy and security.

- *Read more on Horizon 2020*
- *Find out more about the current calls*

Announcement of Upcoming Events

PerMediCon – Personalized Medicine Convention

March 20–21, 2014
Cologne, Germany

For the fourth time, leading experts from the fields of medicine, research, industry and politics will meet on the occasion of PerMediCon (Personalized Medicine Convention) on March 20–21, 2014 in Cologne, Germany. The congress will give ample opportunity to all participants to exchange views on the progress and challenges of personalized medicine and its implications for future health care.

For the first time, PerMediCon will honour three innovative and application-oriented projects which focus on the development of products, technologies and services within the scope of personalized medicine. We are proud to announce that p-medicine is among the 28 projects that are nominated for the award. The project will be presented by USAAR during a session called "Project Slam" on March 20, 2014 and on a poster throughout the entire duration of the congress.

More information

4th Congress of the International Society of Paediatric Oncology (SIOP 2014)

October 22–25, 2014
Toronto, Canada

The 46th Congress of the International Society of Paediatric Oncology (SIOP 2014) promises to attract acclaimed experts from around the world. A stimulating scientific programme will facilitate an exchange of ideas and information on recent findings from a wide variety of specialties. Tailored to a broad range of clinicians, scientists, nurses, allied health professionals, parents and survivors, the world's leading paediatric oncology meeting is an opportunity to engage with a global community of professionals striving to reduce cancer in children.

More information

9th European Breast Cancer Conference (EBCC-9)

March 12–21, 2014
Glasgow, Scotland

European Breast Cancer Conferences (EBCC) series provides a unique multidisciplinary setting for all professionals with a common interest in breast cancer to navigate, discuss, inform and educate themselves about this evolving disease landscape; to debate and deliberate about new data and developments; and to establish what it means for patient treatment and care. Even more importantly, the 9th European Breast Cancer Conference (EBCC-9), the largest Breast Cancer Conference outside the USA, will enable participants to implement the new findings into their daily practice, making a tangible difference for their patients.

More information

23rd Biennial EACR Congress

July 5–8, 2014
Munich, Germany

The 23rd Biennial Congress of the European Association for Cancer Research (EACR-23) expects around 1,800 scientists working in all fields of cancer research to come together to discuss the latest developments in basic and discovery driven translational research, through to personalised cancer treatment. The programme is set out to be highly topical and relevant and to meet the needs of researchers at all stages of their careers. It also aims to provide particular support and encouragement to students and junior researchers. The theme of the 23rd EACR Congress is 'From Basic Research to Personalised Cancer Treatment'.

More information

Since the section of the website on upcoming events is regularly updated we invite you to visit our *website* for most recent changes.

12th Annual Pharma IT Congress 2014/ Clinical Data Congress

September 23–24, 2014
London, United Kingdom

Oxford Global are proud to present the 12th Annual Pharmaceutical IT Congress co-located with the Clinical Data Congress taking place on September 23–24 2014 in London, UK. The decreasing value of clinical trials has put enormous pressure on pharmaceutical companies. During this difficult time alternative solutions are needed to help quicken product timelines and increase profits. This latest addition to our well established Pharmaceutical IT Congress will discuss solutions to tackle the challenge of combining clinical research data and IT systems. Join clinical experts for two days to discover novel data collection methods, the use of real world data in clinical research, and latest advances in clinical trial design.

More information 12th Annual Pharma IT Congress 2014
More information Clinical Data Congress

VPH Conference 2014

September 19–21, 2014
Trondheim, Norway

The date and place for the 3rd VPH conference has been set. The Norwegian University of Science and Technology (NTNU) is very pleased to have been selected by the Virtual Physiological Human Institute to host the upcoming conference. This biannual conference series grew out of the FP7 Virtual Physiological Human Network of Excellence. It has become one of the major instruments for maintaining the coherence and momentum of the highly multidisciplinary VPH community. In the VPH community's view, a substantially improved healthcare can only be achieved through converged efforts of the life sciences, the mathematical sciences and engineering.

Early bird registration deadline: May 8, 2014
Abstract submission deadline: March 30, 2014

More information

2014 ASCO Annual Meeting

May 30–June 3, 2014
Chicago, Illinois

The ASCO Annual Meeting organized by the American Society of Clinical Oncology brings together more than 25,000 oncology professionals from a broad range of specialties, making it an excellent venue for exploring the theme of the Meeting — „Science and Society."

Early registration deadline: April 23

More information

AACR Annual Meeting 2014

April 5–9, 2014
San Diego, California

The 105th Annual Meeting of the American Association for Cancer Research will be held April 5–9, 2014, in San Diego, California. As always, this AACR Annual Meeting will highlight the latest and most exciting discoveries in every area of cancer research, and it will provide a unique opportunity for investigators from all over the world to meet, network, and forge new scientific interactions. This year's Annual Meeting theme, "Harnessing Breakthroughs • Targeting Cures," reflects the great progress being made in cancer research as discoveries in the lab are translated into treatments in an increasingly targeted and precise manner.

More information

BHI International Conference on Biomedical and Health Informatics

June 1–4, 2014
Valencia, Spain

The second BHI'2014 conference is held in Valencia, Spain during June 1–4, 2014 at the Hotel Balneario Las Arenas. The overall theme of the conference is "Translating key health challenges with advances in biomedical informatics." The conference will cover various topics ranging from cutting-edge biomedical and healthcare technology research and development, clinical applications, to biomedical education.

More information

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