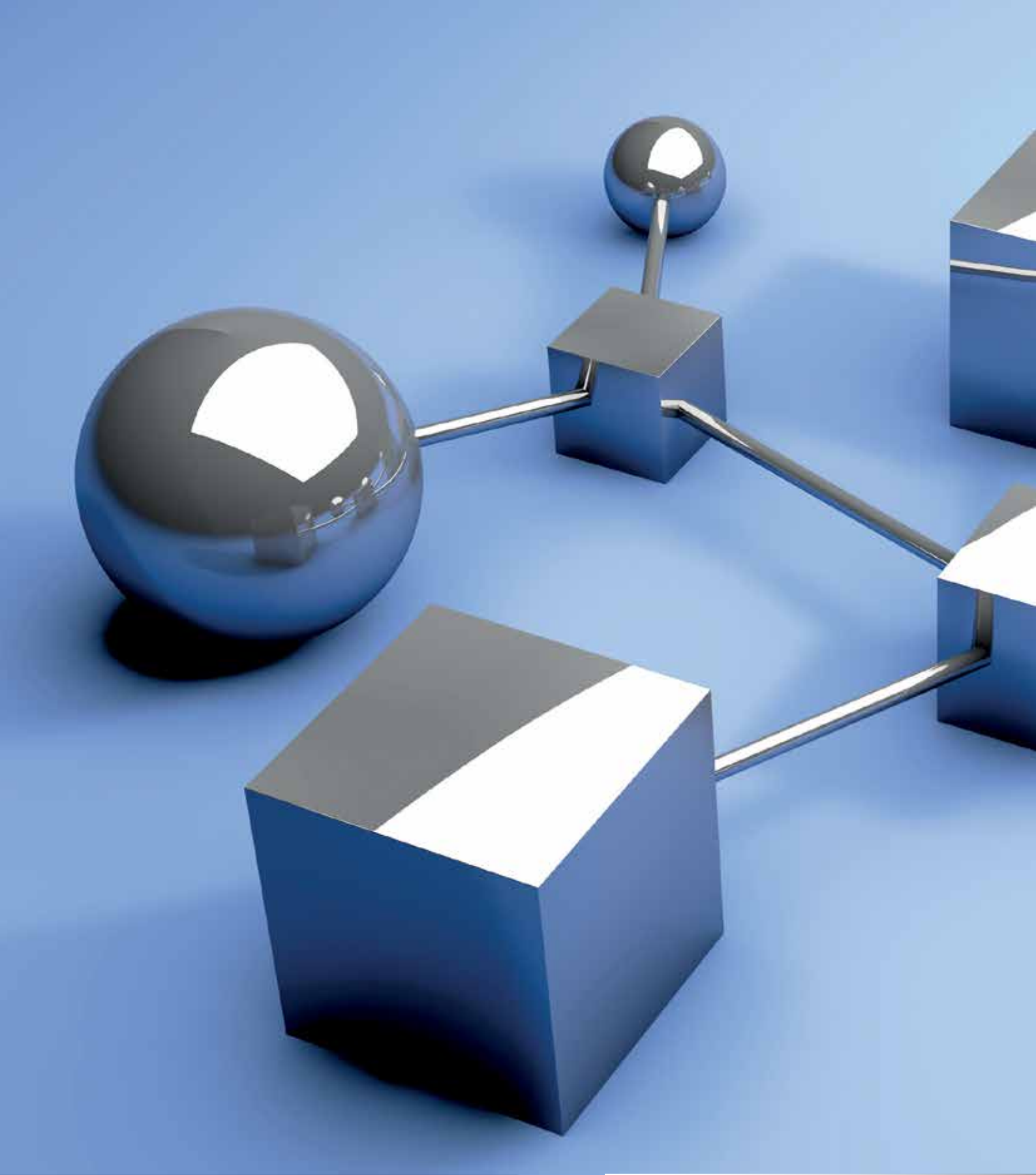


BIOBANKS EUROPE Newsletter

Issue No. 2 / 2015

BBMRI-ERIC
Biobanking and
BioMolecular resources
Research Infrastructure

EDITORIAL - DAY OF ACTION

BBMRI-ERIC is today one of the largest European Research Infrastructure Consortiums (ERICs) ever launched. With the establishment of ERIC, the European Commission responded to requests from EU countries and the scientific community to create a legal framework adapted to the needs of large research endeavours that operate beyond the reach of a single research group or country for the benefit of the European citizen.

BBMRI-ERIC represents 17 Member States and one International Organization. An ERIC "represents an added value in the strengthening and structuring of the European Research Area (ERA) and a significant improvement in the relevant scientific and technological fields at international level" (Council Regulation (EC) No 723/2009, Article 4b).

BBMRI-ERIC aims to generate sustainable tools and procedures for cross-border biobanking in the context of biomedical research. That also means that we need a General Data Protection Regulation (GDPR) that supports such work. The GDPR does not support the ERA enough because transnational research collaborations require legal tools that regulate the exchange of samples and data across national borders. The GDPR could be such a tool. Yet, the present draft seems to have overlooked its impact on research and the ERA by becoming a general and powerful mechanism against the practices of big companies like Google and Facebook.

Prof. Jan-Eric Litton, PhD
Director General of BBMRI-ERIC

That's why BBMRI-ERIC took the imitative for the **Day of Action ‚Data for Health and Science'**, which took place on **16 June 2015 in Brussels** and was recognized as an Editorial **‚Data Overprotection' in Nature** (522, 391-329; 25 June 2015). It brought together patient advocacy groups and research organizations from both industry and the academia from across Europe to engage with EU policy-makers (details p.5). The main goal was to explain how scientific research can be best supported by the proposed GDPR to achieve a knowledge gain not at the cost of research subjects but for the benefit of future patients eventually allowing for speeding up innovation in health care.

The Day of Action consisted of a series of meetings with EU policy-makers as well as a seminar that showed how data is used in research today, which safeguards are already in place, how patients actively participate and why it is important to allow the re-use of data for research purposes.

Moreover, the Day of Action sensitized EU policy-makers on the potential unintended impacts of the GDPR. Ultimately, the Day of Action resulted in four **Recommendations on the General Data Protection Regulation** (p.4).

So, harmonization is needed, especially when Brussels is spending enormous lot of money to create an ERA for Europe but is simultaneously working on a regulation that could hamper this ambition.

Jan-Eric Litton

DATA PROTECTION AND THE PATIENT

People become patients and continue under the care of physicians all their lives. In the event that a patient encounters a serious disease such as cancer, clinicians may propose to take or use samples (tissue, blood…) for research. These samples can be stored in a biobank along with the pertinent data from the patient. This is happening today and should continue in the future.

Patients donate their data and biomaterials for research-only purposes for the benefit of future patients. This gift has to be protected from abuse and from unwanted destruction.

A patient donates data and biomaterials (both are needed; one of them alone is useless) with a broad consent. At the moment of donation it is impossible to indicate possible future research as science is constantly developing and the same biomaterial could become relevant for studies based on new findings, such as looking for the presence of cancer-stem-cells.

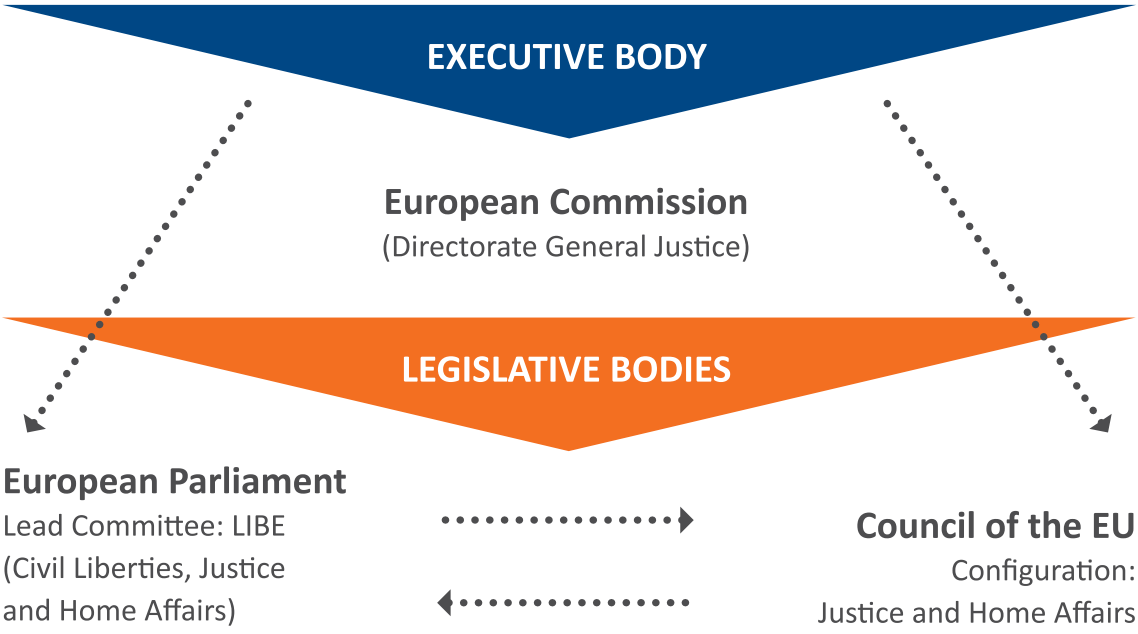
The patient, however, should have the opt-out option with a narrow consent in view of just a very specific project. After the project has finished, future researchers should return to the patient-donor for new consent on new research projects. After the death of the patient, their last consent (broad or narrow) will remain valid, so that research can also continue in the important field of analysing prognostic factors that are a prime concern for patients.

For samples that were donated before the new regulation, every member state should decide on their future use, taking into consideration that patients that donated would be very disappointed if their samples were destroyed as a result of such decisions.

Finally, it is of the highest importance that the regulation should be applied in the same way across the EU (harmonisation), because research needs to operate without borders. For some rare diseases there is only one research centre in Europe, so samples that cannot travel due to lack of harmonisation will hinder this research and cause unwanted harm to the patients suffering from such a rare disease. Patients are waiting for new diagnostic tools and new treatments, results of dedicated research that should be done with great resolve and efficacy.

Between the patient-donor and the research community there is a bond of trust. Any violation of this trust should be punished with fines and penalties that are a clear indication that violating the trust is seen as a serious crime.

Erik Briers, PhD
Board Member EPPOSI
Chair of the BBMRI-ERIC Stakeholder Forum



ABOUT THE GENERAL DATA PROTECTION REGULATION

THE LEGISLATIVE PROCESS

On **25 January 2015**, the **European Commission** published a legislative proposal for a General Data Protection Regulation (GDPR). The centrepiece of existing EU legislation on personal data protection is Directive 95/46/EC of 1995.

The GDPR is intended to replace the current patchwork of national laws with a single set of rules and to take account of the rapid changes of the digital era. The GDPR should make it easier for companies to operate across the European Union while at the same time strengthening citizens' rights, among them the right to be forgotten. The legislative process to come to an agreement on the GDPR involves the European Commission, the European Parliament and the Council of the EU.

The **European Parliament** adopted its version of the draft regulation with 621 votes in favour, 10 against and 22 abstentions on **12 March 2015**, after receiving 3,999 amendment requests in the lead committee alone (Civil Liberties, Justice and Home Affairs). In contrast and following a lengthy deadlock in the Council to agree on a general approach, the Justice Ministers of the 28 Member States of the European Union reached an agreement when meeting in Luxembourg for a Justice and Home Affairs Council on **15 June 2015**.

This agreement allowed the **trilogue process** between the European Commission, Council and Parliament to be started. The first trilogue meeting took place on **16 June**.

The Luxembourg presidency aims to conclude the trilogue by the end of this year. Although all parties involved hope to reach an agreement by the end of this year, this is uncertain as positions between the Parliament and Council are quite diverse. Hence, negotiations may continue into 2016.

‘DATA FOR HEALTH AND SCIENCE’ DAY OF ACTION

On 16 June 2015, a Day of Action led by BBMRI-ERIC was organized in Brussels with the aim of alerting EU policy-makers to the unintended but harmful effects the GDPR could have on statistical, scientific, and historical research and healthcare if strict restrictions – including a requirement for specific consent in science and health research, with only narrow exceptions – are introduced. Well aware that the primary aim of the GDPR is to limit the power of companies like Google and Facebook, participating organizations urged EU policy-makers to recognize the technical and ethical safeguards that already exist in research, and to ensure that the General Data Protection Regulation neither hinders nor roadblocks research and healthcare. BBMRI-ERIC in particular highlighted the challenges of re-consent for both patients and researchers as well as the chance for a single set of laws within the European Union as research is not only transnational but even more so does not know any borders.

Impressions of the Day of Action. 63 participants. 16 speakers. 30 MEP face-to-face meetings.

PARTNER / SUPPORTING ORGANIZATIONS (DAY OF ACTION)

CESSDA, EFPIA, University of Malta, Eurocan Platform, EPPOSI, National Institute for Health and Welfare Helsinki, European Society of Pathologists, INSERM, TMF, Cancer Research UK, Wellcome Trust, Insight, European Cancer Patient Coalition, European Brain Council, BBMRI.nl, Royal Statistical Society, SIB Swiss Institute of Bioinformatic, Karolinska Institutet

DAY OF ACTION RECOMMENDATIONS

1. The Regulation should safeguard the interests of patients in medical research.

Many patient groups say that they do not want to re-consent to each new study, having allowed the usage of their data for scientific purposes for altruistic reasons, especially those with cancer or chronic diseases. Consequently, patients should have the option to donate their data and biomaterials to biobanks and research entities without restricting their consent to a specific study.

This option would allow their data to be used for biomedical research for the benefit of the donors as well as future patients. Many future research purposes are impossible to predict at the time of data collection due to constant developments and progress in science. In addition, continuous re-consent is burdensome for many patients, not least because it reminds patients of their condition. The Regulation should therefore ensure that currently available and future samples and associated data are not wasted, while protecting the data from misuse and illegal disclosure.

2. The Regulation should maintain the distinction between use of personal data for 'historical, statistical or scientific purposes' and data processing, which is potentially harmful to data subjects.

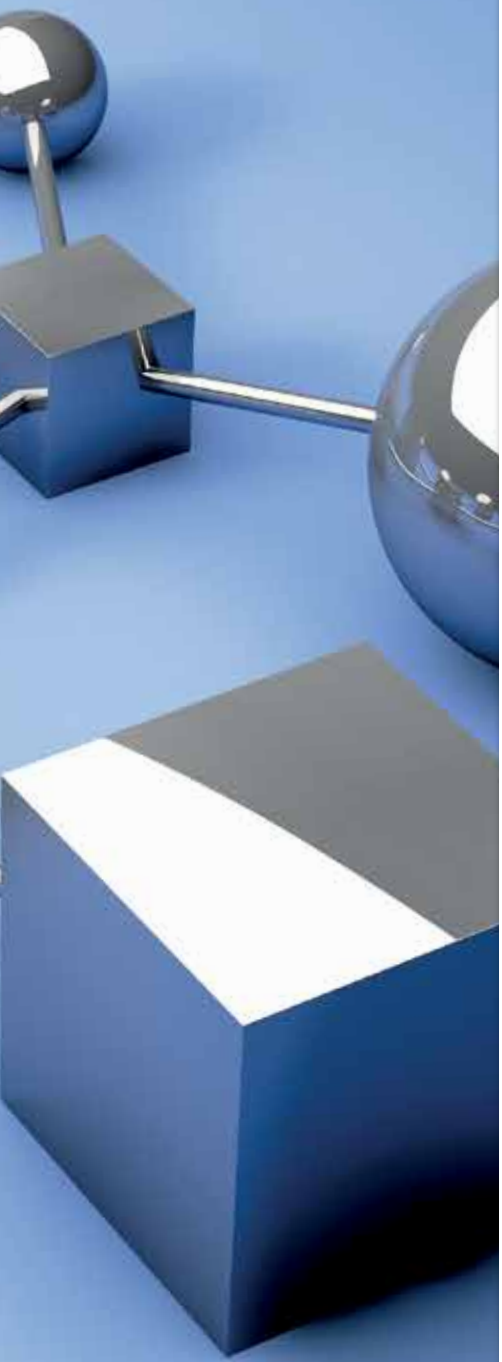
Historical, statistical and scientific research delivers benefits to society using personal data and currently protects privacy through various ethical, governance and technical safeguards.

The Regulation should highlight the importance of such safeguards to protect data subjects. Existing safeguards include approval of research uses of personal data by ethics committees, legal agreements which detail appropriate use of data, pseudonymisation of personal data, and confidentiality safeguards. Institutions such as the Council of Europe and the European Group on Ethics produce codes and recommendations on how best to protect participants from potential harm resulting from participation in research. In the case of medical research, high standards of patient safety have been ensured by adherence to ethical principles set by policy instruments such as the Declaration of Helsinki, the EU Clinical Trials Regulation, and the ICH Good Clinical Practice.

3. Harmonised rules for research at EU level would be preferable to promote transnational research collaboration. At the same time, the harmonised rules should not lead to a deterioration of the status quo for research. In particular, harmonised rules would be extremely valuable for rare diseases, as Pan-European studies are often necessary to obtain sufficient data, given the small numbers of patients affected across a single country.

4. The Council's approach, which provides derogations to Member States with respect to consent for historical, scientific, and statistical research, **should be maintained** to avoid negative effects on research.

This is particularly important for biomedical research, which is a highly controlled area with many safeguards in place to protect the confidentiality of information about patients.



In a Nutshell

„Health research should be exempt from the requirement for informed consent in cases of public interest, for example to allow disease or patient registries set up for improving diagnoses, especially on rare diseases and other health registries to continue to operate."

„There are many cases where especially the requirement of re-consent would make research highly impracticable for both research participants and researchers alike. Mechanisms to protect privacy and at the same time to include and inform research participants actively already exist in research, including pseudonymisation, approval by research ethics committees, opportunities for opting out of further processing, biomedical practices and confidentiality rules. Such safeguards protect privacy without hindering research unlike a requirement for specific consent for every new research study."

„The General Data Protection Regulation could be the opportunity to facilitate a simplified cross-border research and data exchange. Exclusively leaving the decision to provide an exemption to Member States will only maintain the current legal fragmentation and encumber cross-border research within the EU."

„Health research, especially research biobanks, store biological material and data for future studies that are not yet specifiable and thus work typically with a model of consent for biomedical research that allows to use the entrusted data for many study designs and disease groups. People who allowed the usage of their data for scientific purposes have largely done so for altruistic reasons and tend to suffer from 'consent fatigue', especially when they themselves or their kin have become patients; not wanting to be reminded repeatedly of their illness by receiving requests for study participations. Typically, re-consenting results in the attitude of research participants accepting the consent without reading it, therewith contradicting the concept of 'informed consent' altogether."

FAQ

What is a Directive?

It is a legislative instrument that is binding on the Member States to whom it is addressed as regards the result to be attained but leaves them free to determine the form and methods.

Directives may be adopted under the EC Treaty either by the European Parliament and the Council or by the Council or by the Commission. Once adopted, Community Directives still have to be transposed by each of the Member States, that is to say they must be implemented in national law.

What is a Regulation?

It is an instrument of general scope that is binding in its entirety and directly applicable in all Member States. Regulations can be adopted under the EC Treaty by the European Parliament and the Council or by the Council or by the Commission. Regulations are often used in the field of judicial cooperation in civil matters. They are directly applicable, so they require no transposition into the Member States' domestic law and directly confer rights or impose obligations.

What is the Trilogue?

Describes tripartite meetings attended by representatives of the European Parliament, the Council and the Commission with the aim of reaching a common position on the proposed text.

What are the key differences between the three GDPR versions as regards to research?

Whereas the Commission's proposal recognises that specific consent is often not possible, the European Parliament reduced research exemptions significantly, requiring specific consent for each new research question. In return, the Council maintained key exceptions for research but reinforces a strong flexibility for Member States, thereby contradicting the purpose of the GDPR to find one set of rules for the EU.

When will the GDPR come into force?

Two years after the date of publication.

NATURE EDITORIAL

Nature 522, 391-392 (25 June 2015); online: http://www.nature.com/news/data-over-protection-1.17825.

Reporting on the Day of Action, the editorial agrees with the concerns of data overprotection and advocates a proper research exemption to the GDPR. Ultimately, it argues that a pan-European law on how data could be sourced, stored and used could be beneficial for research, because greater harmonization could smooth the difficulties that scientists face especially in research collaborations across national borders. 'Data overprotection.

Draft European rules governing privacy threaten to hamper medical research.'

EUROBAROMETER STUDY

http://ec.europa.eu/justice/newsroom/data-protection/news/240615_en.htm

The Data Protection Eurobarometer study conducted in March 2015 with almost 28,000 face-to-face interviews across the European Union concludes that respondents have serious thoughts about the consequences of their data being collected, processed and used. At the same time, respondents firmly believe that borders should not confine protection of personal data. Nine out of ten Europeans (89%) believe that they should have the same level of protection over their personal information, regardless of the country in which the authority or private company processing their data is based.

COMMISSION PROPOSAL

http://www.europarl.europa.eu/RegData/docs_autres_institutions/commission_europeenne/com/2012/0011/COM_COM%282012%290011_EN.pdf

COUNCIL VERSION

http://data.consilium.europa.eu/doc/document/ST-9565-2015-INIT/en/pdf

PARLIAMENT VERSION

http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P7-TA-2014-0212+0+DOC+XML+V0//EN

INTRODUCING THE FINISH NATIONAL NODE

Facts & Figures

Number of Biobanks/Partners of the Consortium:
BBMRI.fi consists of 9 partner biobanks and biobank initiatives:

1) Auria Biobank: University of Turku and hospital districts of Southwest Finland, Satakunta and Vaasa

2) THL Biobank: National Institute for Health and Welfare (THL)

3) FHRB Biobank: Finish Hematology Registry, Finnish Red Cross Blood Service and FIMM

4) HUB Biobank: Hospital district of Helsinki and Uusimaa and University of Helsinki, FIMM

5) AMCH Biobank: Hospital district of Helsinki and Uusimaa (HUS; HYKS ERVA), UH

6) Northern Finland Biobank Borealis: Oulu University Hospital, University of Oulu, NordLab and the healthcare districts of Kainuu, Lapland, Central Ostrobothnia and Länsi-Pohja

7) Tampere Biobank Initiative: Pirkanmaa Hospital District (PSHP), University of Tampere (UTA), the joint municipal authority of the Etelä-Pohjanmaa hospital district (EPSHP) and the joint municipal authority of the Kanta-Häme hospital district (KHSHP)

8) Eastern Finland Biobank Initiative: Eastern Finland Biobank Initiative (Hospital District of Northern Savo, University of Eastern Finland, and Hospital Districts of Itä-Savo and Etelä-Savo and North Karelia Central Hospital and Honkalampi Centre)

9) Central Finland Biobank initiative: Central Finland Health Care District (KSSHP) and University of Jyväskylä (UJ)

Funding:
Joint infrastructure coordination funding for the BBMRI.fi network: 500,000 €/year. Additionally, the Academy of Finland has provided up to 800,000 €/year competing funding for biobank equipment. Additionally, biobanks invest their own institutional funding for structure and operation of approx. 6M €/year.

Available Samples:
Tissue,
number of samples: 6,808,732
DNA,
number of donors: 199,561
Serum/plasma,
number of donors: 1,075,504

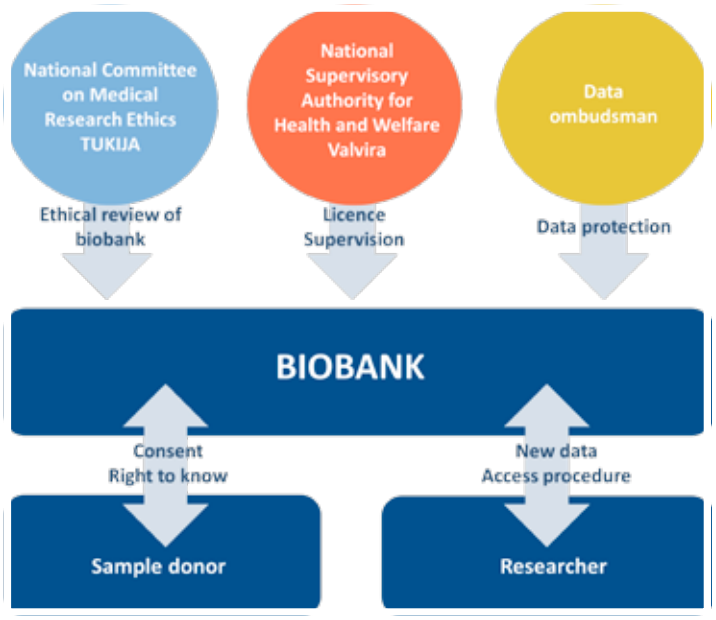
Dr. Jalanko. Why is biobanking important to you personally, and what can be achieved by it that would otherwise not be possible?

Biobanking is important to me personally because I believe that biobanks can contribute to improving health care. We can make a difference by collaborating together and sharing the valuable biological resources for more efficient research in promoting health, diagnostics and new treatments. I have developed a very close relationship to biobanking by following a major success: More than 20 years ago, Leena Peltonen introduced the idea to collect DNA samples in Finnish population cohorts, and now these samples have been used in major international collaborations. Both the genetic as well as health data that are available today have tremendously increased the value of these established cohorts. Thus, I have

experienced myself close up how high quality biobank-related research can bring new discoveries over time – and these cohorts remain a model also for modern biobanking.

Finland is among the few countries that have a biobanking law. Tell us more about it.

The Finnish Biobank Act [www.finlex.fi] has been effective since September 2013. It is a unique piece of legislation; its major principles are the protection of privacy, the right to know, the possibility to transfer all study collections of universities, hospitals, and research institutions to registered biobanks, and the broad consent model that allows that samples and data can be used for future research. The act also specifically allows both research and product development. The National Supervisory Authority for Health and Welfare administers a registration status for biobanks and requires high-level data protection, quality standards, proper administrative processes and transparent access procedures as specified in the Biobank Act. This imposes strict duties on registered biobanks and has resulted in the establishment of large national biobanks by the National



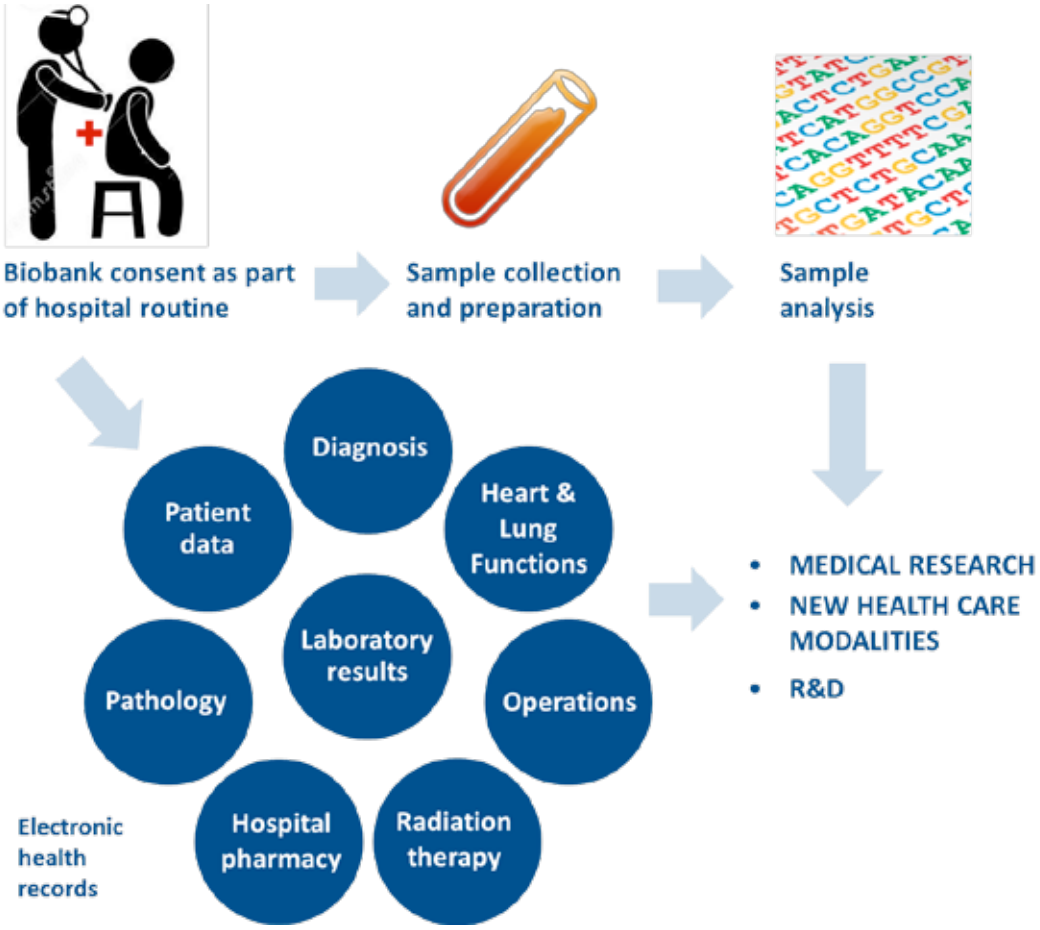
Biobanking and Supervision

Institute for Health and Welfare as well as hospital districts together with universities. Currently, 6 biobanks are already registered and 3 biobank initiatives are undergoing the registration process.

What is particular/specific strength of Finnish biobanks?

As all Finnish biobanks are members of BBMRI.fi, we now have the unique possibility to coordinate the access as well as quality and data harmonization of major sample collections of universities, hospitals and research institutions. New samples and data can now be collected directly in the context of the hospital workflow of clinical care, ensuring quality and usability of both samples and data in high-class research and product development. Besides academic research projects, the first among the registered clinical biobanks, namely Auria and THL Biobanks have already initiated significant public-private partnerships. Most importantly, the Finnish biobanks have initiated the process of building a one-stop access portal for biobank resources. The strength of BBMRI.fi is also that we can rely on both top experts and scientists to work together on building the national infrastructure. For me, this is the key to success, because new scientific breakthroughs, new biomarkers and personalized treatment can only be achieved in collaboration with both top-level scientists and medical companies.

New samples and data collected in the hospital workflow



What are the next challenges for BBMRI-ERIC in general, and BBMRI.fi in particular?

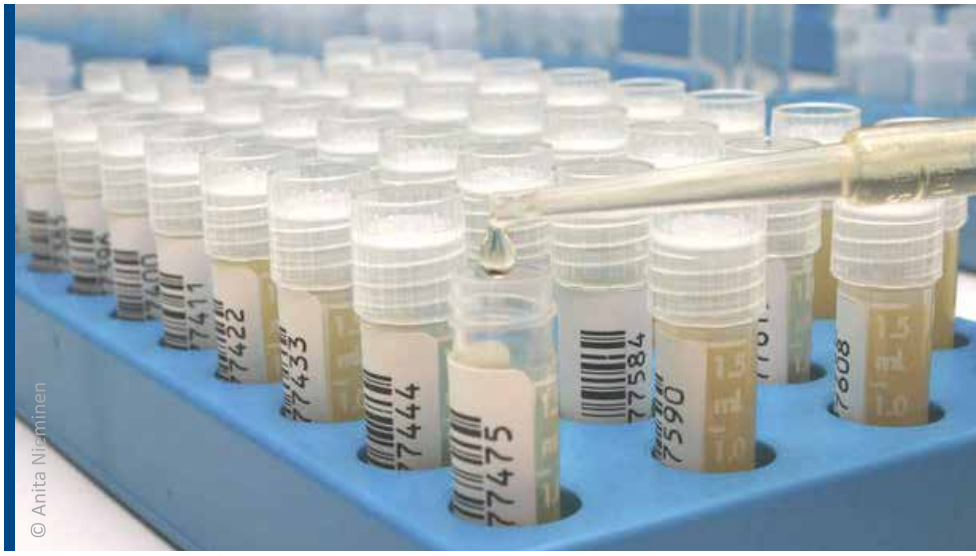
The sustainability of biobanks is a major concern all over Europe. It will be necessary to develop jointly accepted procedures for public-private collaboration, especially since academic resources will not be enough to realize the full potential of biobanks. A second challenge for both BBMRI-ERIC and for BBMRI.fi is the harmonization of hospital data. Finland aims to be a role model for Europe in that regard, as we are currently initiating a national enterprise to develop an integration tool for clinical data of hospitals. Big Data is also a huge challenge for biobanks since the growing amounts of genomic and imaging data need to be stored and utilized efficiently, but also must follow the rules of handling of sensitive data. Another important challenge is to obtain a smooth access procedure of BBMRI-ERIC biobanks. Currently, BBMRI-LPC [www.bbmri-lpc.org] is providing access to large prospective cohorts and collects observational data for BBMRI-ERIC of the access procedure. It has become clear that access procedures need to be harmonized and smoothened throughout Europe. Access provision should become established as a key performance indicator followed in all BBMRI-ERIC biobanks! The current coordination programme of BBMRI.fi is built on similar major pillars as BBMRI-ERIC, namely:

- Integration of Finnish biobanks to the operations of BBMRI-ERIC
- Implementation of a harmonized access procedure for biobank samples and related data
- Centralized administration of biobank availability services and coordination of biobank IT solutions
- Providing quality standards for biobanks
- Providing ethical and legal services

Successful availability services for biobank samples and data are essential for future success and BBMRI.fi is actively participating in the implementation of BBMRI-ERIC Directory as well as the planning of the Common Service IT in order to contribute to the BBMRI-ERIC Sample Locator – the Gateway for Health.

What are in your opinion the current challenges at the European level?

My strong belief is that if we can integrate the biobanks through BBMRI-ERIC and get public acceptance for public-private partnerships – in ethically sound circumstances – we have succeeded. Ultimately, it will be important to integrate biobank operations more closely with health care to speed up the translation. Public acceptance is essential and the biobanks have a huge responsibility in seeing that the collaborative projects with pharma will truly end for public benefit from bench to bedside.



What in your opinion can be achieved through BBMRI-ERIC?

We can show that collaboration of European biobanks can lead to a one-stop shop for biobank samples and data as well as to other biological resources. However, we need to implement this very soon. Developing the BBMRI-ERIC Expert Centre concept into a truly functional model will be a prerequisite for efficient utilization of biobanks. It has to be ensured that the samples and data stored in biobanks are used in the best way possible for the advancement of health care.

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BIOSKETCH

Anu Jalanko, PhD,
Research Manager, Head of Unit
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National Institute for Health and Welfare (THL)

I have been extremely fortunate because I could make my research career surrounded by top scientists like Leena Peltonen, who thought me to always reach for the best and to truly aim at making a difference while promoting health.

My own career as a research director concentrated on molecular mechanisms of Finnish rare diseases, which complemented nicely to the genetic findings of a number of rare metabolic disorders. The results have been published in major high impact journals, most actively in Human Molecular Genetics and I have supervised 13 PhD theses. Currently, I am involved in research projects developing new techniques for iPS cells to be utilized in biobank research. I have been coordinating one major EU project on rare diseases, NCL-Models and I have participated as a PI in two Centres of Excellence of the Academy of Finland and obtained major grants from the Acamey of Finland and other funding agencies. I have been a member of several scientific societies and currently hold board memberships of several institutes and infrastructures. Also, I have been organising several international congresses, the latest being HandsOn Biobanks 2014 in Helsinki.

I have been fortunate to participate in several pioneering research infrastructures in Finland and the most famous achievement of my unit at THL was to automatize DNA extraction, aliquoting and logistics to efficiently use the DNA samples for whole genome association analyses as well as more recently for whole genome sequencing. All of this has been possible due to excellent skills of the researchers and infrastructure experts that we have been able to recruit to THL.

More recently, I have been enthusiastically developing the concept of biobanking since we had to establish a legal biobank to THL, which was successfully completed in March 2014. Also here, I have been fortunate

CARING ABOUT QUALITY

Dr. Haslacher. You are the QM Coordinator of BBMRI.at, which comprises a variety of different biobanks. How many biobanks work together in BBMRI.at?

In Austria, professional biobanking has a comparably short tradition. The national biobank landscape evolved during the last decade and is closely connected to the medical universities and their associated university hospitals.

Moreover, the degree of organisation is quite variable. Whereas the Medical Univer-

to rely on the best colleagues imaginable to build this major Finnish infrastructure. Since 2014, I am officially nominated as the National Coordinator of BBMRI.fi. I have coordinated the BBMRI.fi network since 2011 together with the Finnish biobank actors and participated in the Preparatory Phase as well as the Preparatory Body of BBMRI.

My current position is Head of Genomics and Biomarker Unit at the National Institute for Health and Welfare at THL. The Unit houses THL Biobank, high-profile research groups as well as a biobank service laboratory and a biomarker service laboratory, with a total of 60 full-time employees. The Unit is studying genetic and molecular mechanisms behind several diseases and the researchers of the unit hold remarkable scientific merits, especially in genetic epidemiology.

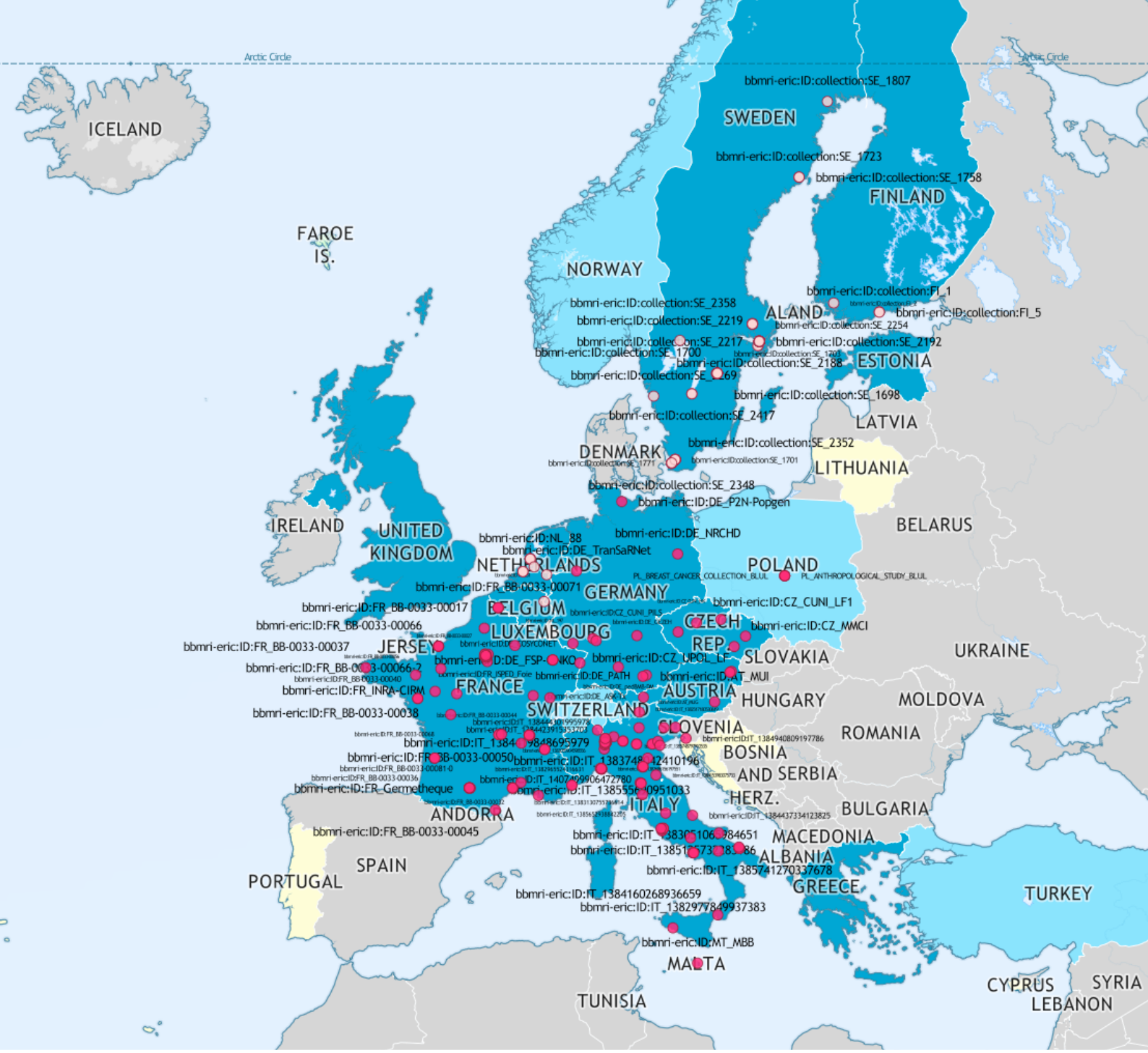
I am responsible for the THL Biobank and under my leadership we have organized all the legal biobank processes. Our unit hosts the DNA samples of the majority of Finnish population cohorts, with samples from 200,000 individuals. Currently, samples and data from 110,000 study participants have been transferred to the registered THL Biobank. The biobank service laboratory is operated together with the Institute for Molecular Medicine FIMM and our responsibility is the automated DNA extraction, processing, storage, aliquoting and shipping for research projects.

Enthusiasm towards biobanking is important, but most important is family, friends and activities. I have been extremely fortunate to have a great husband with whom I share all my free-time activities, the current top activity being golf – together with friends.

I have two wonderful sons and three incredible grandchildren. I have lots of love in my life and that makes me very strong.

sities of Graz (Biobank Graz) and Vienna (MedUni Wien Biobank) as well as the University of Veterinary Medicine (VMV) run large-scale, centralised biobanking facilities, biobanks are developing through the merger of existing collections at the Medical Universities of Innsbruck and Salzburg.Besides medical universities, BBMRI. at is complemented by the Life Science Governance Institute as well as the Alpe-Adria University of Klagenfurt, which provide valuable input regarding ELSI and data management issues respectively.

Read the full interview with and learn more about quality at: *http://www.bbmri-eric.eu/quality*



BBMRI-ERIC DIRECTORY 1.0 NOW AVAILABLE

We are proud to announce that you can now find biobank samples and data of interest using the new BBMRI-ERIC directory service. It contains more than 500 biobanks and standalone collections. This is the first service in the portfolio of BBMRI-ERIC IT tools to be delivered during years 2015-2017. It is focused on enabling users to explore the infrastructure of BBMRI-ERIC, to communicate with the biobanks, to identify the biobanks samples and data of interest, and to negotiate access with the sample/data custodians. BBMRI-ERIC is also committed to developing tools relevant for other stakeholders beyond sample and data requesters, such as patient bodies, data protection and funding agencies.

The Directory will allow biomedical and bioinformatics users to identify biobanks that might potentially have samples and/or data of interest for their research, jointly developed by the BBMRI-ERIC and all its National Nodes. The Directory is open for browsing, as well as for search through the available data, including but not limited to available material types, diagnoses, accompanying data.

As of now, two user interfaces are provided. Showcasing modularity of the Directory and capability of integration in further applications:

- *http://bbmri-eric.eu/bbmri-eric-directory*

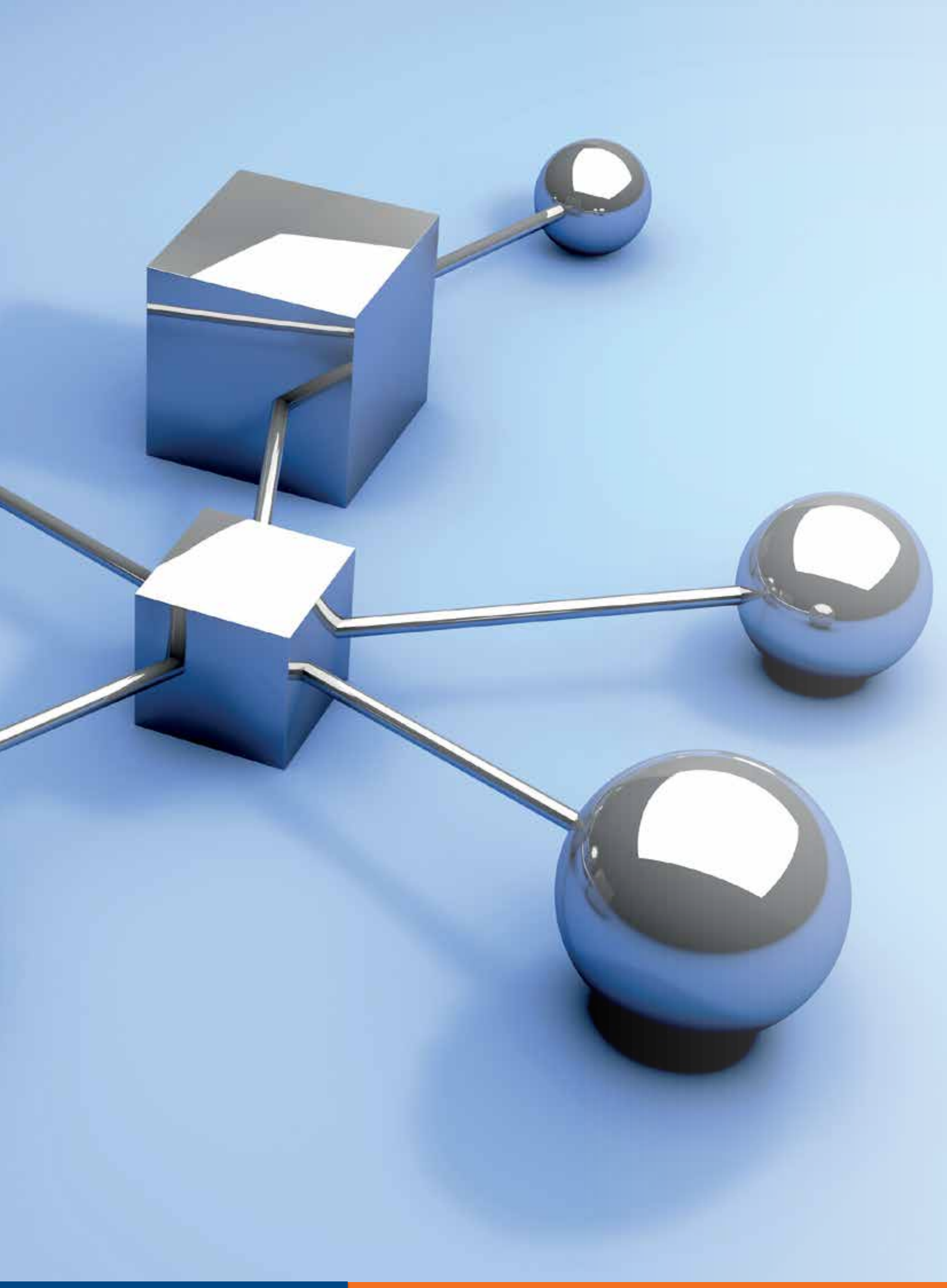
integrated directly into the website of BBMRI-ERIC, developed in close collaboration with BBMRI.at National Node utilizing the LifeRay portal technology,

- *http://directory-molgenis.bbmri-eric.eu*

integrated with the BBMRI.nl National Node catalogue, developed in collaboration with BBMRI.nl National Node using MOLGENIS framework.

At this phase, the requesters will need to communicate with the biobanks of interest on individual basis, but this will be further improved by another tool called Sample Broker, due to be delivered by mid-2016. The Directory is build using a clean internal component-based architecture, with clear separation of the information storage and querying from the human-readable and machine readable interfaces. Internally, it utilizes distributed LDAP architecture, with translation to JSON interfaces to allow for an easy integration into now popular REST APIs for direct integration in other applications. The distributed nature of the LDAP/REST-based architecture follows the hub-and-spokes architecture of BBMRI-ERIC, enabling the National Nodes and local biobanks to retain full control on what information they provide.

The BBMRI-ERIC Directory is closely coupled with the development of the MIABIS 2.0 standard; with further updates (Directory 2.0) being scheduled for fall 2015, accompanied with publishing of the core components of the MIABIS 2.0 standard. BBMRI-ERIC is now also setting up the Common Service IT in order to ensure sustainable long-term delivery and operation of the IT tools, including BBMRI-ERIC Directory service.



HandsOn Biobanks 2016 - "Biobanks for Health Innovation"

HandsOn Biobanks (HOBB) 2016 will focus on the role of biobanks in health innovation with special focus on health research data management viewed from technical, ethical and legal standpoints. Participants will have the opportunity to join "hands on" activities, such as implementing European quality standards, testing IT tools for public engagement, and taking part in an ethics café in a classical Viennese coffee house. A "pitch your innovative concept show" should stimulate collaboration with companies offering innovative products for biobanking and companies requiring access to biobanks to develop their products.

HOBB 2016 will be organized in association with the **International Biobanking Summit** and the **BBMRI-LPC Forum meeting 2016.**

CONTACT

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TOPICS

- **CE and ISO standards: HandsOn training for implementation**
- **General data protection regulation an its impact on medical research**
- **An emerging new era for data management**
- **Pitch your innovation concept**
  a roadshow of innovative business ideas/concepts related to biobanking for partnering
- **Medical imaging and biobanking**
- **New tools for public engagement**
- **Ethics café in a classical Viennese coffee house**

LOCATION

Garden Palace Liechtenstein | Fürstengasse 1, 1090 Vienna, AUSTRIA | www.palaisliechtenstein.com

Front picture: YLOG paraffin tissue archive of BioBank Graz, immunoflourescence staining of HepG2 cells (both Medical University of Graz)

Photo: Elias Freiberger

IMPRINT

PHILOSOPHY, NATURE AND PURPOSE OF BUSINESS

„Biobanks Europe“ is the newsletter of BBMRI-ERIC, designed to facilitate the joint establishment and operation of Research Infrastructures of European interest and beyond. The ERIC status allows pulling together biobanks and biomolecular resources into a pan-European facility and providing access to collections of partner biobanks and biomolecular resources, their expertise and services on a non-economic basis. BBMRI-ERIC is established for an unlimited period of time.

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