



BBMRI-ERIC

Biobanking and
BioMolecular resources
Research Infrastructure

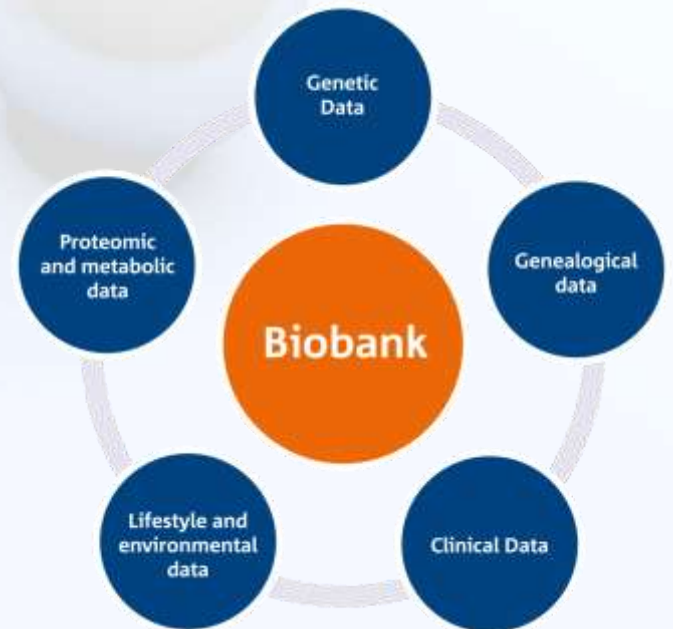
Introduction to coordination of biobanks In Europe - BBMRI-ERIC

Prof. Jan-Eric Litton
Director General

www.bbmri-eric.eu

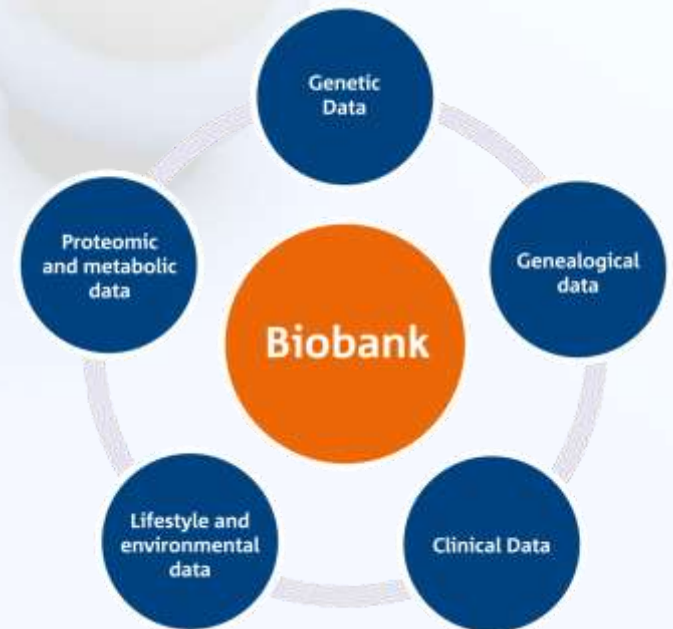
Welcome to the BBMRI family

BBMRI.uk



BBMRI

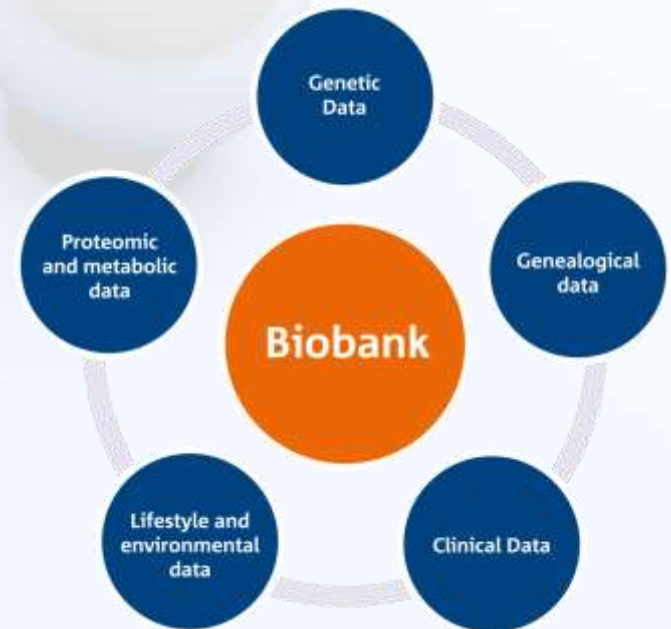
Biobanking and BioMolecular resources Research Infrastructure



BBMRI- ERIC

Biobanking and BioMolecular resources Research Infrastructure

European Research Infrastructure Consortium



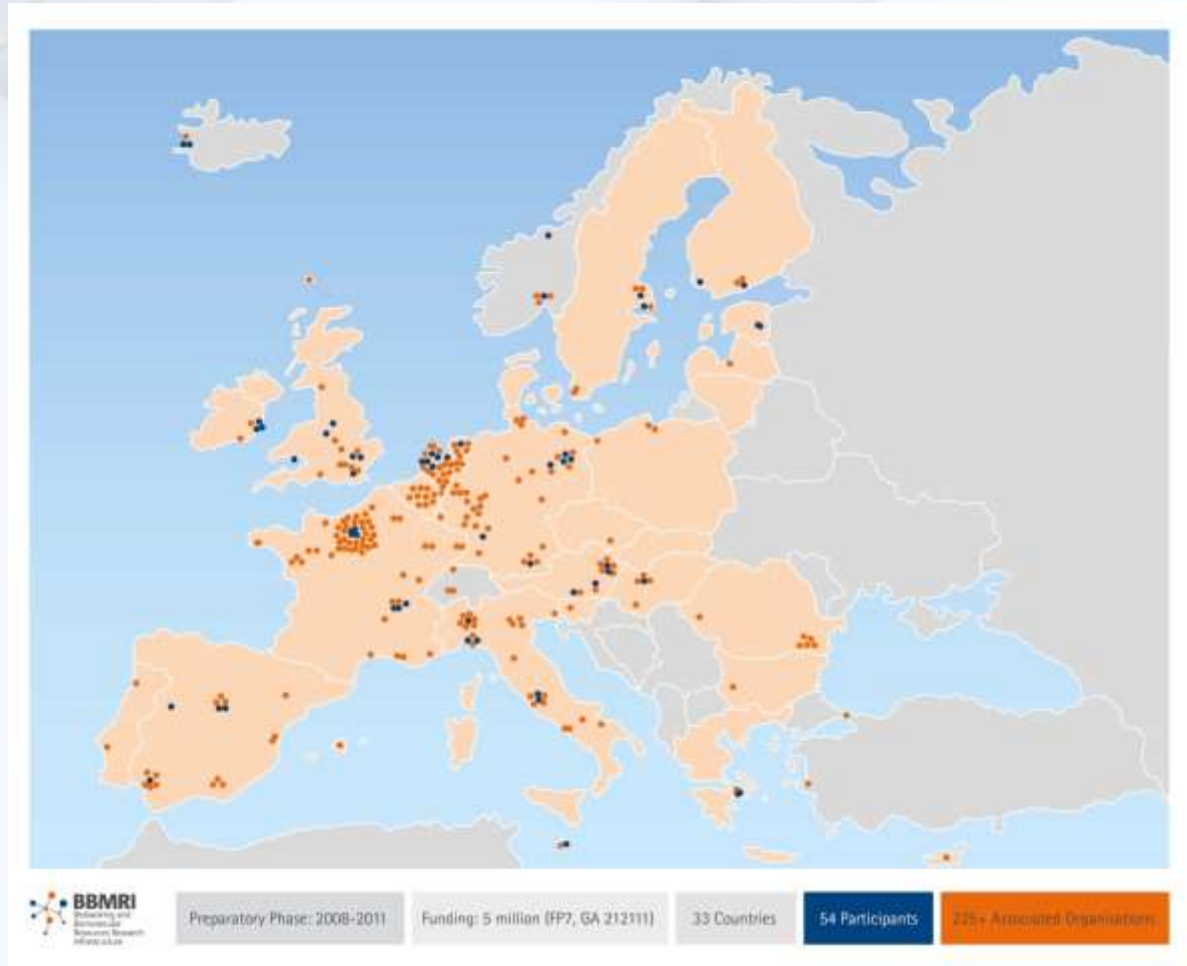
History of BBMRI

1st ESFRI Roadmap

This roadmap proposes research facilities of pan-European interest
 Among BBMRI



The Preparatory Phase of BBMRI 2008 - 2011



BBMRI towards BBMRI-ERIC

BBMRI PP(2008-211) to BBMRI-ERIC – The Interim Phase (2011-2013)

31 January 2011



7 July 2013

Application

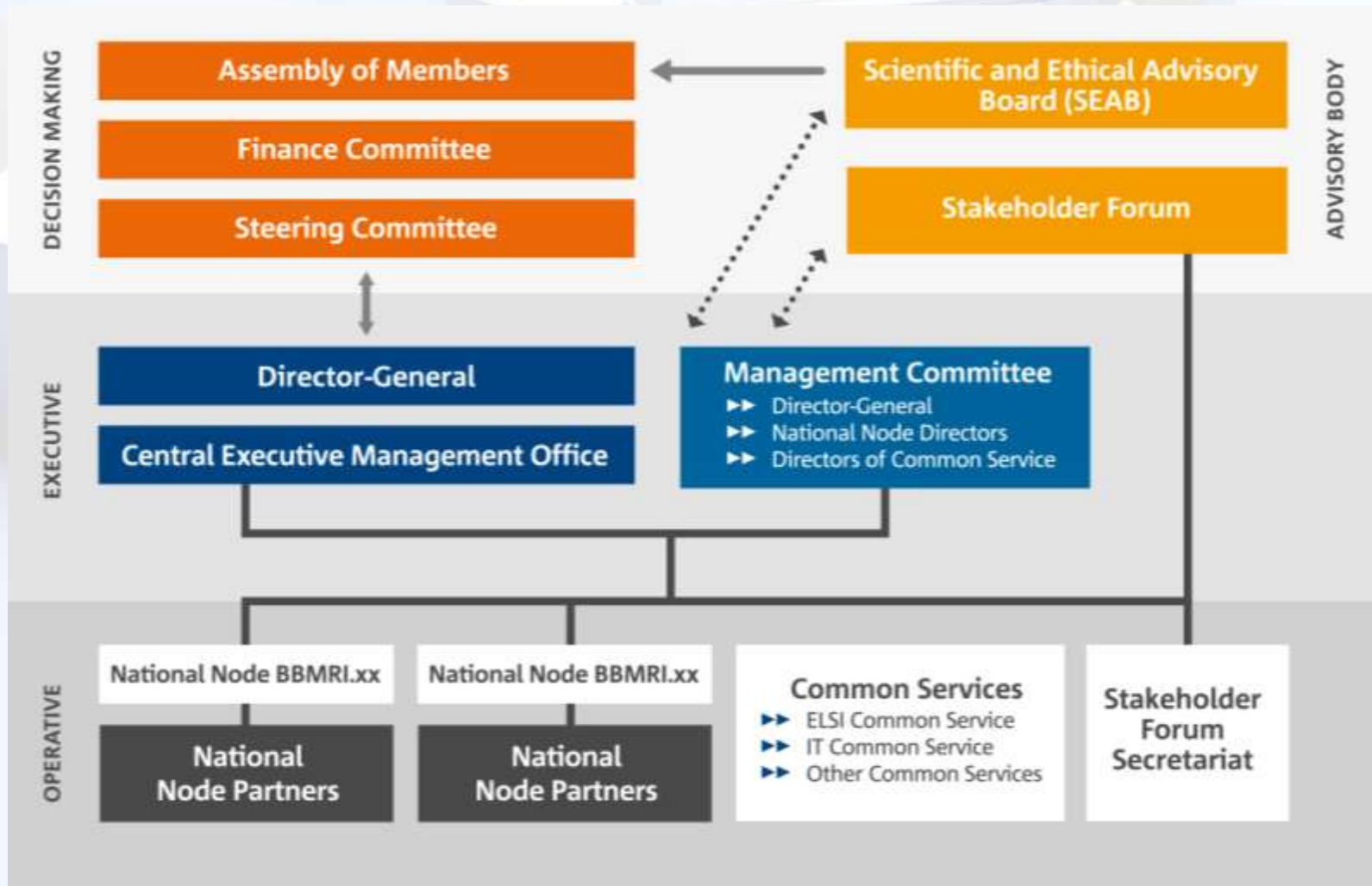


3 December 2013

Awarded ERIC Status



GOVERNANCE STRUCTURE



BBMRI-ERIC - largest infrastructure in health in Europe

Founding Members of BBMRI-ERIC

Austria
Belgium
Czech Republic
Estonia
Finland
France
Germany
Greece
Italy
Malta
Netherlands
Sweden
United Kingdom

Official Observers of BBMRI-ERIC

Norway
Poland
Switzerland
Turkey
IARC



BBMRI - LPC Forum in Budapest 24-25 September 2015

Eastern Europe

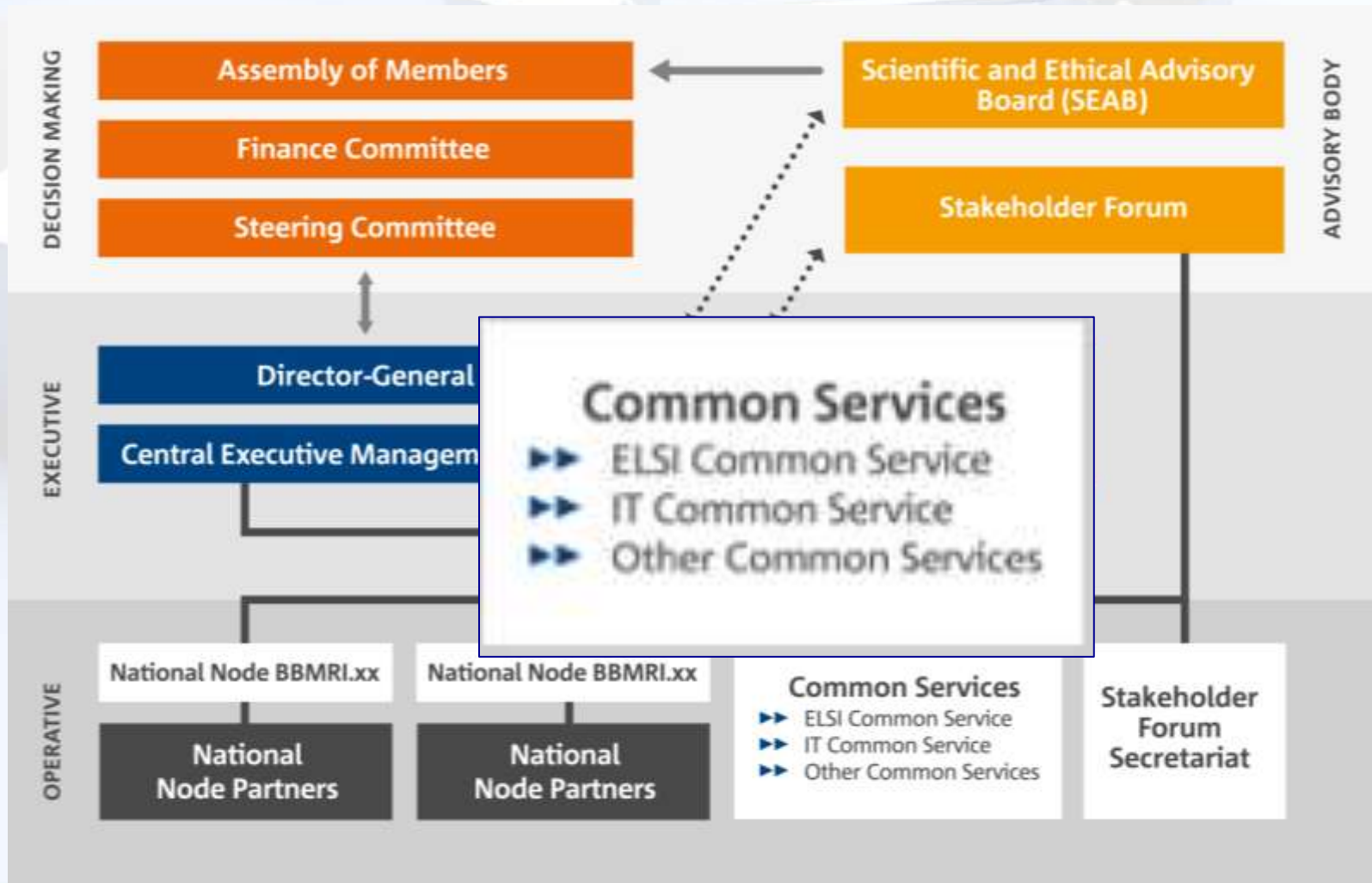
Bulgaria
Croatia
Cyprus
Georgia
Kosovo
Latvia
Lithuania
Russia
Slovak Republic
Slovenia
Ukraine

Non Europe

Ghana
Israel
Kuwait
Vietnam



GOVERNANCE STRUCTURE



Common Service ELSI

Prof. Anne Combon-Thomsen

- Advise in ethical reviews
- Provide ethics check for research proposals
- Monitor ELSI aspects related to biobanking
- Follow up on relevant legislation/regulations
- Help-Desk to provide practical guidance on ELSI issues
- Organise experience sharing
- Prepare & maintain tools and services
- Disseminate results of latest ELSI research



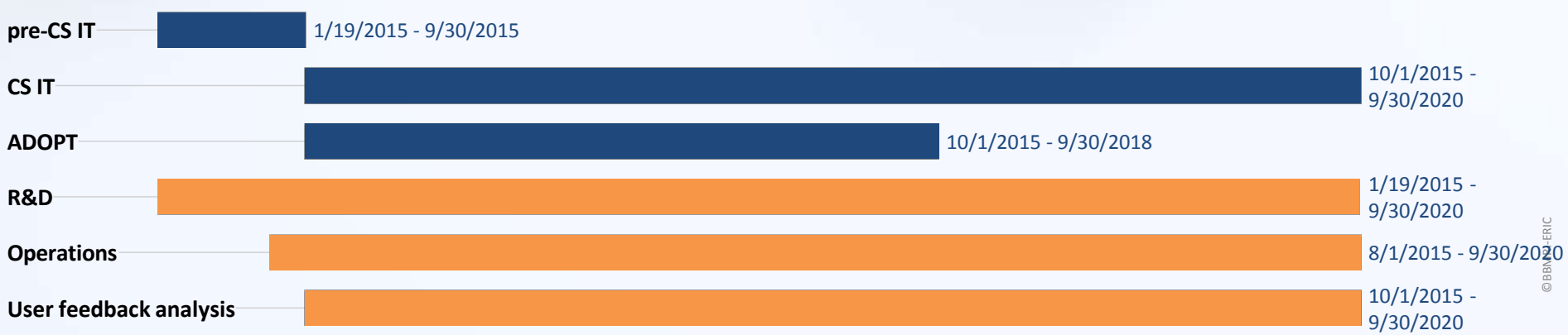
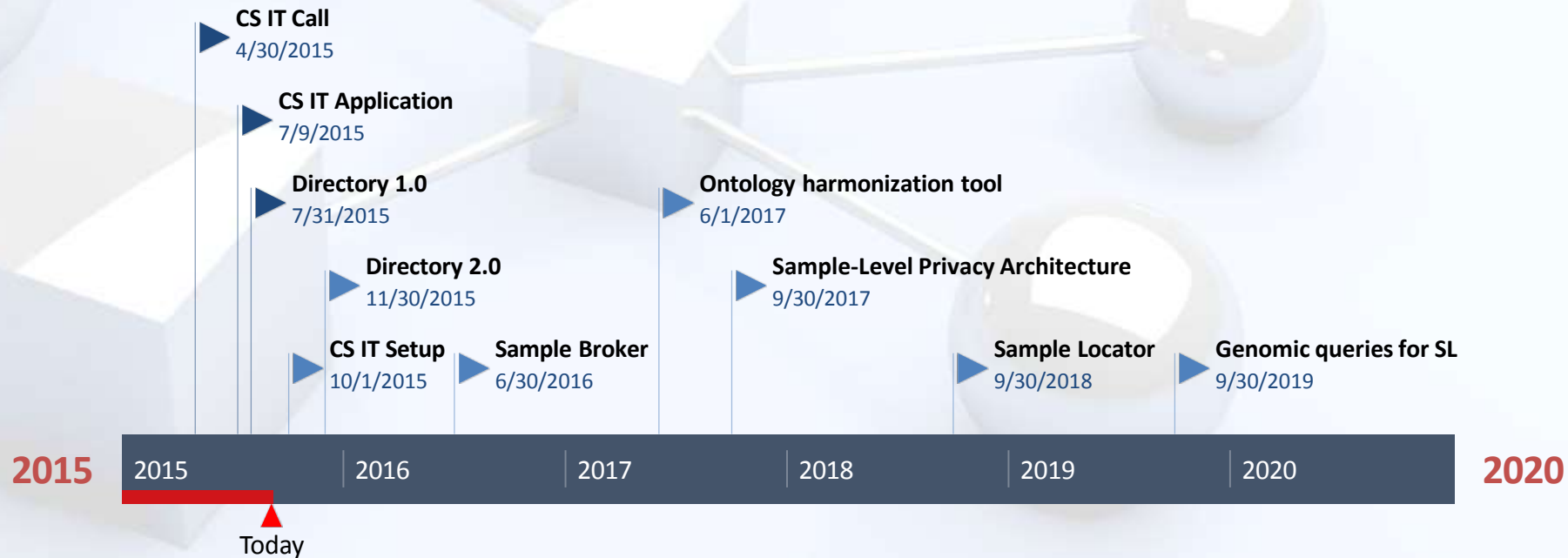
BBMRI-ERIC Common Service ELSI

Paris 8-9 September 2015

- *Workshop: Sharing and Access to data and Human Bios for the benefit for the patient*
- *Toward a BBMRI-ERIC Policy For Sharing and Access*

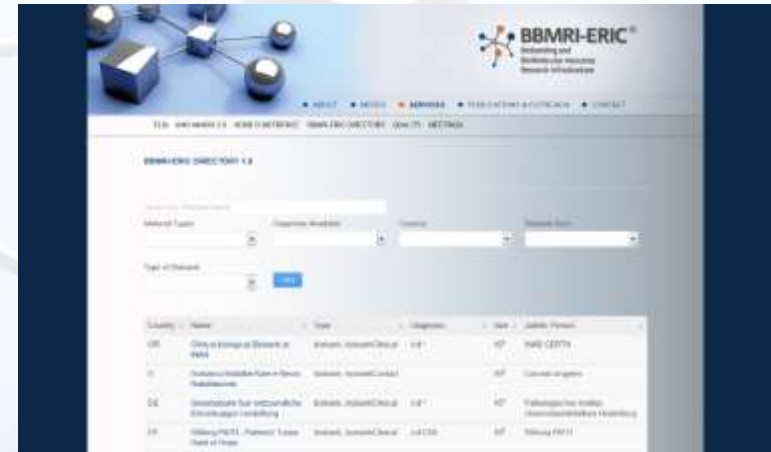
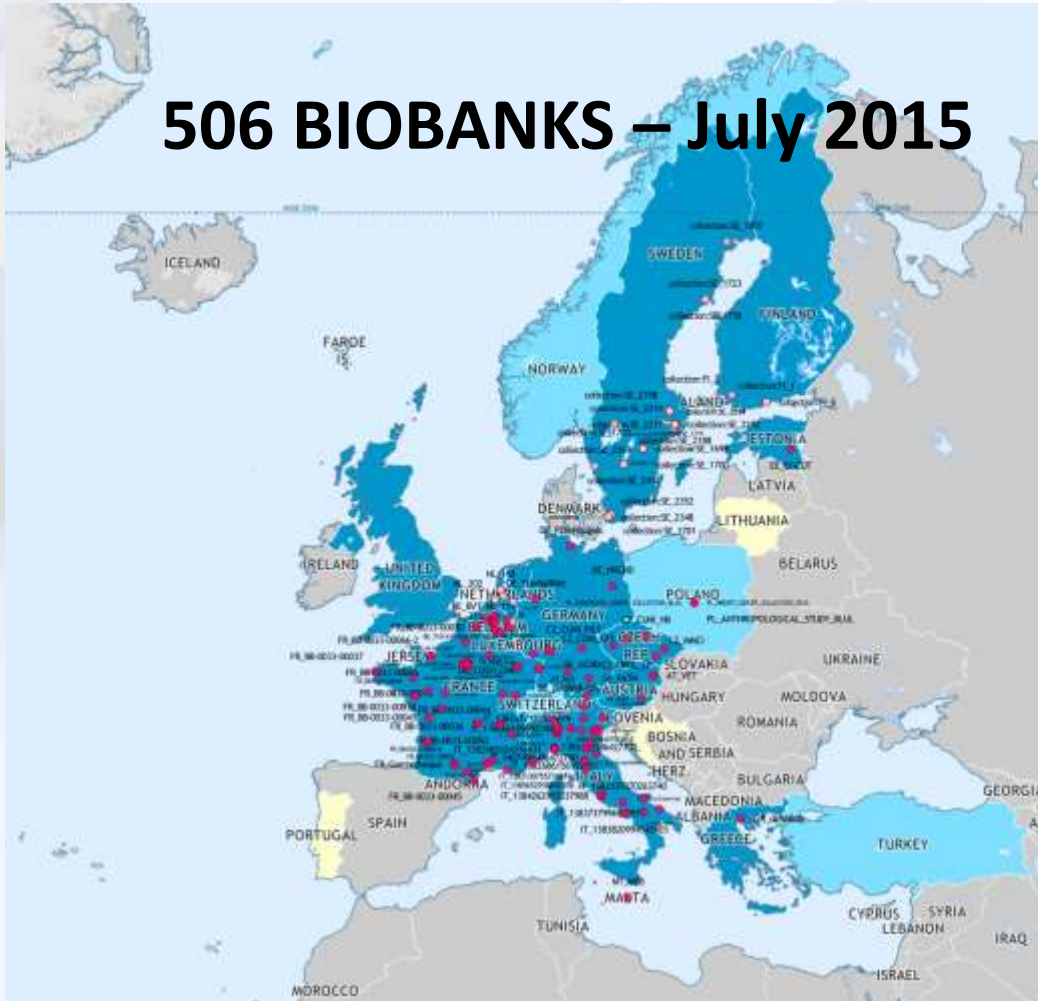


BBMRI-ERIC IT

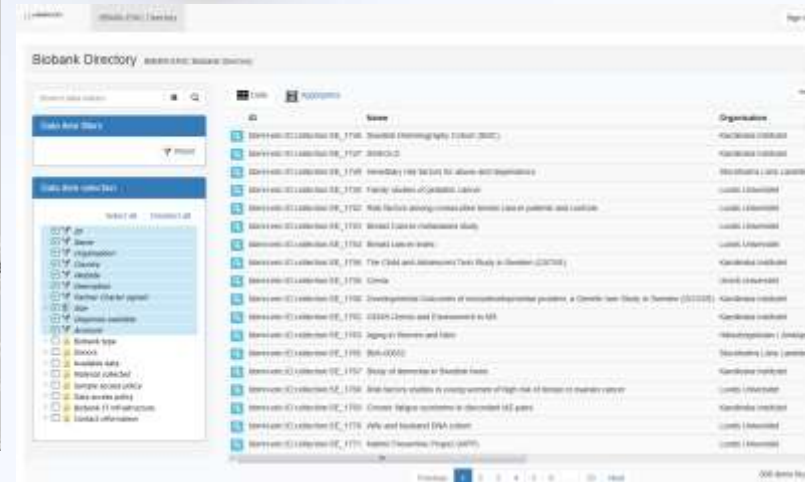


Directory 1.0

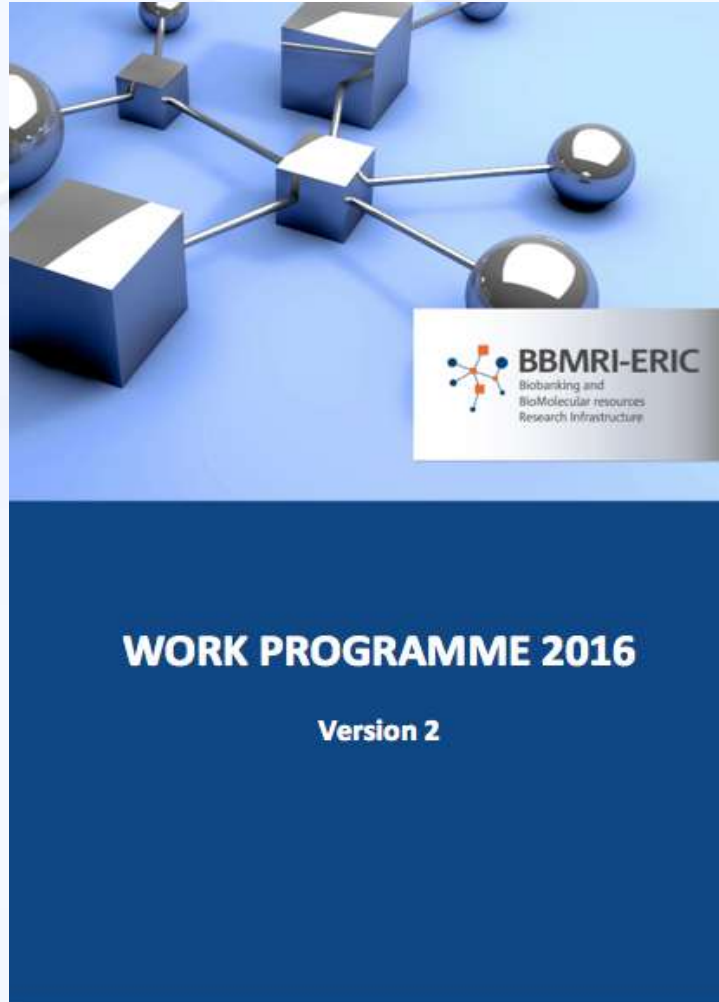
506 BIOBANKS – July 2015



2 USER INTERFACES



Work Programme 2016



Access

- procedure and rules (for data and sample access)
- cost model (definition)
- ELSI



bbmri-lpc

BBMRI - Large Prospective Cohorts

BBMRI-ERIC full member of RD-connect

RD  Connect

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EVENTS ▾

NEWS ▾



An integrated platform connecting databases, registries, biobanks and clinical bioinformatics for rare disease research

About RD-Connect

Fragmentation of research data makes rare disease research more difficult. RD-Connect links it all together, globally. | [read more](#) |

News

ADOPT BBMRI-ERIC

INFRADEV-3 2015, Individual implementation and operation of ESFRI projects

“Prioritisation of support to ESFRI Projects for implementation” from 7 April 2014.

- organise national biobanks and establish what each country will precisely offer in terms of data and services and amalgamate these efforts,
- increase discoverability and access to data by setting up infrastructure, standards and tools for data sharing whilst protecting privacy, and harmonies data and IT across biobanks,
- fully develop access procedures and services for the researchers,
- fully develop a Common Services to all ethical, legal and societal issues related to access to personal data, and involving all relevant sectors,
- enhance the connection between basic research through to the clinic,
- establish Common Services on rare diseases,
- support steps to continue expanding the membership of BBMRI-ERIC .



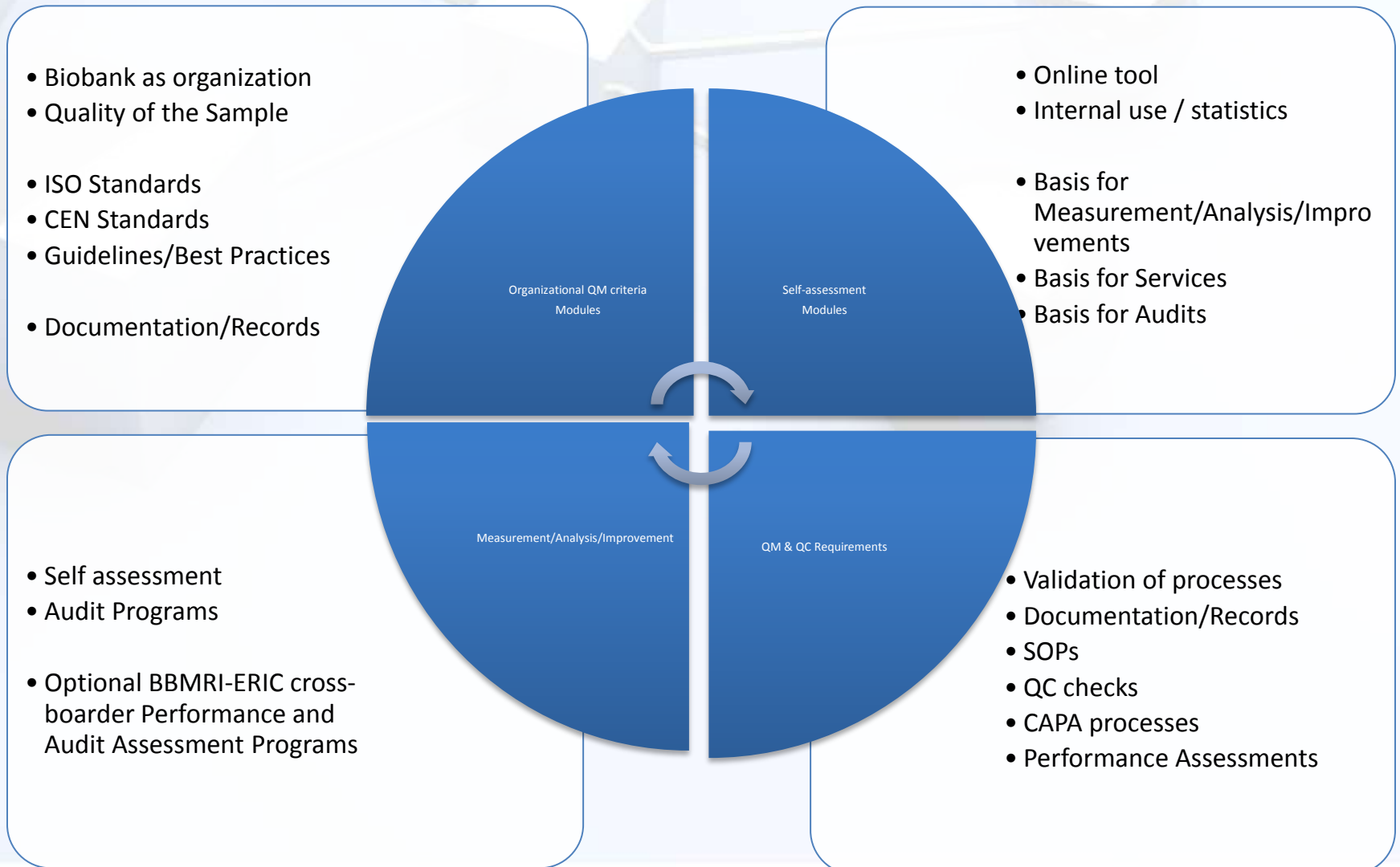
SAMPLE QUALITY

“Pre-analytical errors still account for nearly 60%-70% of all problems occurring in laboratory diagnostics, most of them attributable to mishandling procedures during collection, handling, preparing or storing the specimens”.

Lippi G. *et al.*. Preanalytical quality improvement: from dream to reality. *Clin Chem Lab Med.* 2011 Jul; 49(7):1113-26. Epub 2011 Apr 25.



BBMRI-ERIC Q-Strategy



BBMRI-ERIC SEAB MEMBERS

Mr. Alastair Kent -OBE Director of Genetic Alliance UK



- Alastair Kent OBE is the Director of Genetic Alliance UK – the national charity of over 180 patient organisations, supporting all those affected by genetic conditions. Genetic Alliance UK’s mission is to promote the development of the scientific understanding of genetics and the part that genetic factors play in health and disease, and to see the speedy transfer of this new knowledge into improved services and support for patients.
- Alastair is also the Chair of Rare Disease UK (RDUK) the national alliance for people with rare diseases and all who support them. RDUK has over 1,500 members including over 250 patient organisations, health professionals, researchers, the pharmaceutical industry and individual patients and families.
- Alastair has worked in the field of genetic and rare disease healthcare for over 20 years. Alastair represents the interests of patients on numerous platforms; he is the president of the European Genetic Alliances Network (EGAN), Immediate Past Chair of the European Platform for Patient Organisations, Science and Industry (EPPOSI) and the EU Committee of Experts on Rare Diseases amongst others. He has previously been a member of the Orphan Medicinal Products Committee and Committee for Advanced Therapies at the European Medicines Agency and a member of the Human Genetics Commission.

BBMRI-ERIC SEAB MEMBERS

Dr. Anders Ekblom, MD, PhD, DDS -Senior Advisor at Phase4 Partners Limited.



- Dr. Anders Ekblom, MD, PhD, DDS is a Senior Advisor at Phase4 Partners Limited. Dr. Ekblom is an Associate Professor at Karolinska Institutet. He has an extensive experience as an executive and leader with broad business knowledge from senior roles in the biopharmaceutical industry, with global working cross functions and different countries delivering products, projects, productivity and change management. He has managed staff and projects in United States, European Union and Asia. Dr. Ekblom has 14 years of experience in senior medical and research positions.
- During 19 years at AstraZeneca, he was a member of global executive teams holding different senior roles including Executive Vice President of Global Medicines Development, Global Head Clinical Development, Global Therapy Area Head, Global Head Science and Technology Integration, and Chief Executive Officer at AstraZeneca AB Sweden. Dr. Ekblom served as Executive Vice President of Global Drug Development at AstraZeneca plc since January 1, 2009. At AstraZeneca, Dr. Ekblom was responsible for the global clinical development function, delivering across all clinical stages of drug development including lifecycle management, and leading staff at all major R&D sites. He also served as Executive Vice President of Development of AstraZeneca PLC since January 01, 2009.
- His experience spans a number of therapy areas including licensing and alliance management. He serves as Director of AnaMar AB. He serves as a Non-Executive Board Member at the Karolinska University Hospital, with Biotech companies and a Senior Advisor. Dr. Ekblom served as a Director of Albireo AB. He was recognised as "one of the 100 best managers in Pharma Industry" by PharmaVOICE in 2006. He has 60 scientific publications in peer reviewed journals and additional publications such as book chapters. Dr. Ekblom is a Doctor of Dental Surgery, a Medical Doctor, holds a Board certification in Anaesthesiology and Intensive Care and a PhD and Associate Professorship in Physiology from the Karolinska Institute, Stockholm.

BBMRI-ERIC SEAB MEMBERS

Prof. Carolyn Compton, MD, PhD - Professor of Life Sciences Arizona State University



- Dr. Carolyn Compton is an academic pathologist who received her MD and PhD degrees from Harvard Medical School. At ASU, she is the Chief Medical and Science Officer of the National Biomarkers Development Alliance, a member of the Biodesign Institute and the Chief Medical Officer of the Complex Adaptive Systems Initiative. Her research interests are related to colon cancer, bio-banking and biomarkers development.
- She was a professor of pathology at Harvard and Massachusetts General Hospital, Chair of Pathology at McGill University from 2000-2005, and Director of the Office of Biorepositories and Biospecimen Research at the National Cancer Institute until 2012. She is the past CEO and President of the Critical Path Institute.
- Compton is an adjunct professor of pathology at both the University of Arizona and Johns Hopkins, and research associate at Mayo Clinic.

BBMRI-ERIC SEAB MEMBERS

Mr. David Byrne – Director of Pathwell Ltd, Dublin, Ireland



- David Byrne was appointed EU Commissioner in 1999 and held the portfolio of Health and Consumer Affairs during the Prodi Commission, when he established the European Centre for Disease Control (ECDC) and the European Food Safety Authority (EFSA). Prior to that, he served as Attorney General in Ireland.
- Currently, he chairs the Board of Global Action for Health Institute (GA4Hi) and he is Director of Pathwell Limited.
- Mr. Byrne is an Honorary Fellow of the Royal College of Physicians (London) and the Royal College of Physicians in Ireland. In 2004, he was conferred with the degree of Honorary Doctor of Laws by the National University of Ireland. He is Chancellor emeritus Dublin City University.
- A lawyer by training, Mr. Byrne practiced as a Senior Counsel in the Courts of Ireland and the European Court of Justice before his appointment as Attorney General of Ireland in 1997.

BBMRI-ERIC SEAB MEMBERS

**Assoc. Prof. Mark Daly - Center for Human Genetic Research at
Massachusetts General Hospital/Harvard Medical School**



- **Mark J. Daly, PhD is an Assistant Professor at the new Center for Human Genetic Research at Massachusetts General Hospital/Harvard Medical School and is also an Associate Member of the Broad Institute of Harvard and MIT, where he directs computational biology for the Medical and Population Genetics Program.**
- **His lab focuses on computational approaches to understanding the genetics of disease with a strategy of integrating techniques from both human and mouse genetics. The lab has extensive experience in linkage and association analysis and is now primarily focused on the creation of haplotype maps in humans and mice, the development of methods for the design and interpretation of association studies using these maps, and the specific application of these approaches in major common disease areas such as diabetes, inflammatory/autoimmune disease and neuropsychiatric disease.**
- **Mark holds a BS in physics from the Massachusetts Institute of Technology and a PhD in Genetics from Leiden University.**

BBMRI-ERIC SEAB MEMBERS

Dr. Thomas J. Hudson - President and Scientific Director of the Ontario Institute for Cancer Research



- Dr. Thomas J. Hudson is President and Scientific Director of the Ontario Institute for Cancer Research, which focuses on translational research in prevention, detection, diagnosis and treatment of cancer. Dr. Hudson is internationally renowned for his work in genomics and human genome variation. Past positions include leadership roles as Founder and Director of the McGill University and Genome Quebec Innovation Centre, and Assistant-Director of the Whitehead/MIT Center for Genome Research, where he led a team that generated physical and gene maps of the human and mouse genomes.
- He is a founding member of the International Haplotype Map Consortium and the Public Population Project in Genomics (P3G), Dr. Hudson was instrumental in the creation of the International Cancer Genome Consortium and chairs the Consortium’s Executive and Scientific Steering Committees.
- Dr. Hudson was appointed an Officer of the Order of Canada in 2013 and is a Fellow of the Royal Society of Canada. Other awards include the 2014 Jerry Dolovich Memorial Lectureship Award, the 2012 Champion of Genetics Award from the Canadian GeneCure Foundation, the 2010 Annual Harry and Edith Gladstein Professor Award from the Indiana University School of Medicine, the 2005 Achievement of the Year in Healthcare from Maclean’s magazine, the 2005 Award for Research in Immunology by the Canadian Society of Allergy and Clinical Immunology, an Investigator Award from the Canadian Institutes of Health Research, a Burroughs-Wellcome Clinician-Scientist Award, The 2002 Prix de la Santé from the Armand-Frappier Foundation, the 2001 Young Scientist Award by the Genetics Society of Canada, the 2000 Scientist of the Year by Radio-Canada, and the 1999 Canada’s Top 40 Under 40.



Welcome to the BBMRI family

BBMRI.uk





BBMRI-ERIC
gateway for health

Thank you!
[*jan-eric.litton@bbmri-eric.eu*](mailto:jan-eric.litton@bbmri-eric.eu)

