

Break-out session: **Nordic Collaboration within Biobank Sciences**

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Leader Nordic Biobank Network

ESFRI

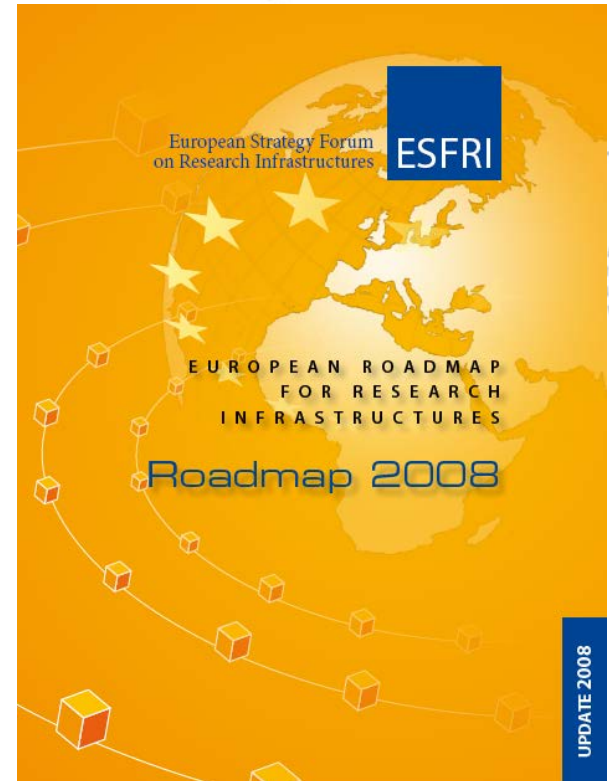
European Strategy Forum of Research Infrastructure

Biological and Medical Sciences

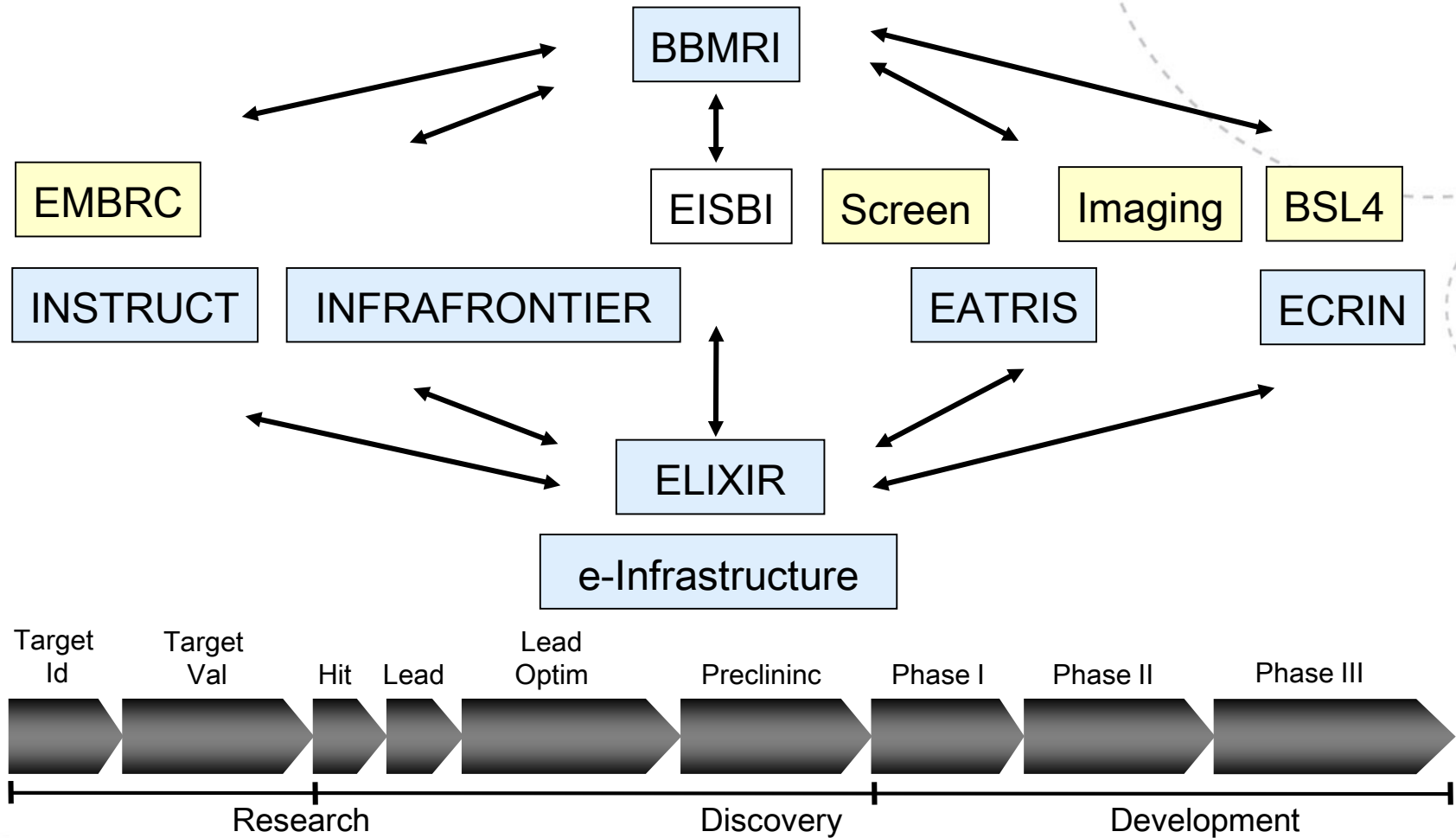
- **BBMRI**
- EATRIS
- ECRIN
- ELIXIR
- EMBRC
- EU-OPENSSCREEN
- EuroBioImaging
- High Security BLS4 Laboratory
- Infrafrontier
- INSTRUMENT

<http://cordis.europa.eu/esfri/>

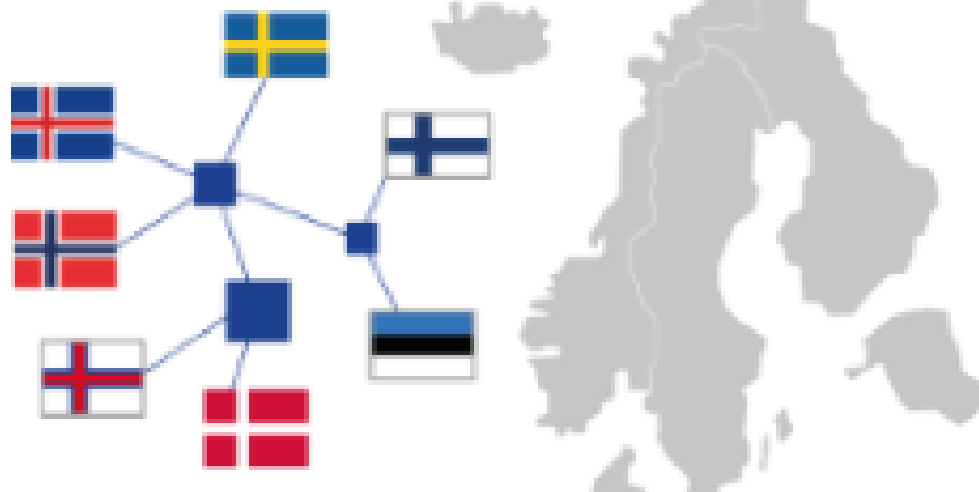
**BBMRI-ERIC was established in 2013. First General Director:
Prof. Jan-Eric Litton, KI , Sweden**



Potential synergies of Research Infrastructures for drug development

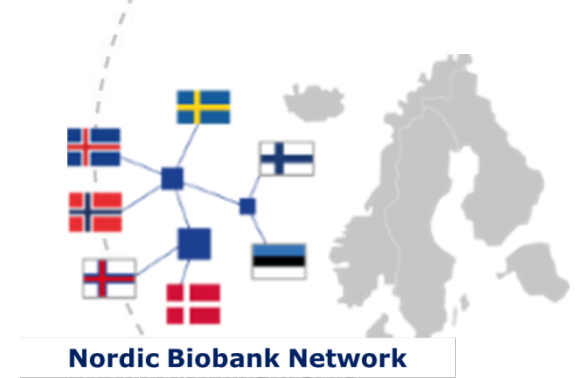


Nordic Biobank Network



Nordic Biobank Network

Biobank.nordic



- Established in February 2010 – supported by NordForsk
- An interim Nordic biobank network within BBMRI to consolidate and further develop the Nordic biobank collaboration awaiting the establishment of BBMRI-ERIC
- Lead by BBMRI.se (Jan-Eric Litton) until January 2014
- Reorganized as a Nordic Biobank Network from 2014, to be lead by BBMRI.no (K Hveem) for the coming 2 years
- Includes **Sweden, Norway, Finland, Denmark, Island, Faroy Island and Estonia**

Characteristics of Nordic biobanks

- High quality of samples and large sample collections
- State of the art biobanks with automated and high throughput technologies
- Diverse sample collections, not only DNA
- Good and validated QA/QC procedures
- Access to clinical endpoints
- Available analytic competence
- Transparency
- Strong focus ethics
- Proactive towards industrial collaboration

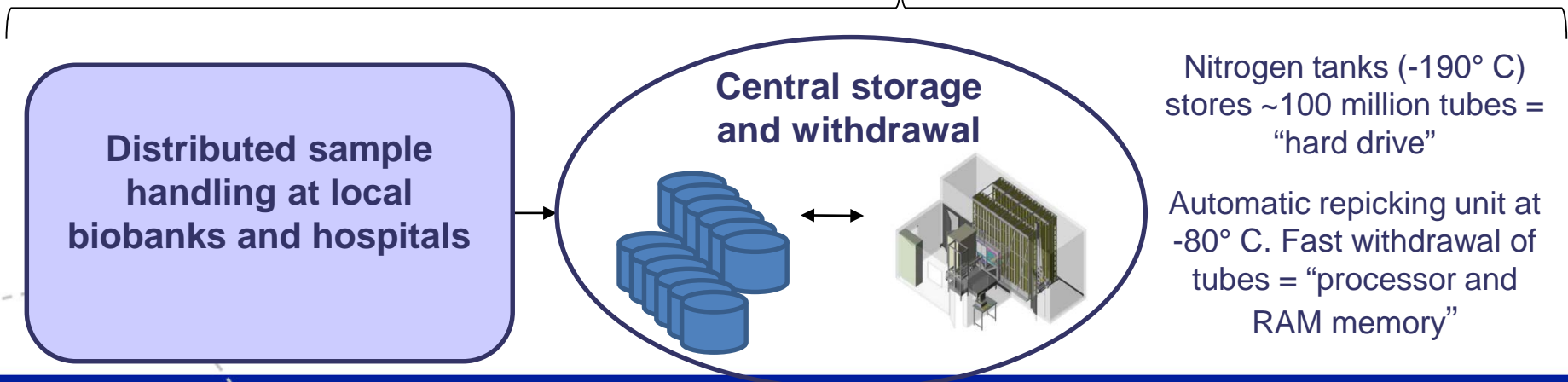
Nordic national biobank infrastructures

Contains probably more 100 million samples from several million contributors

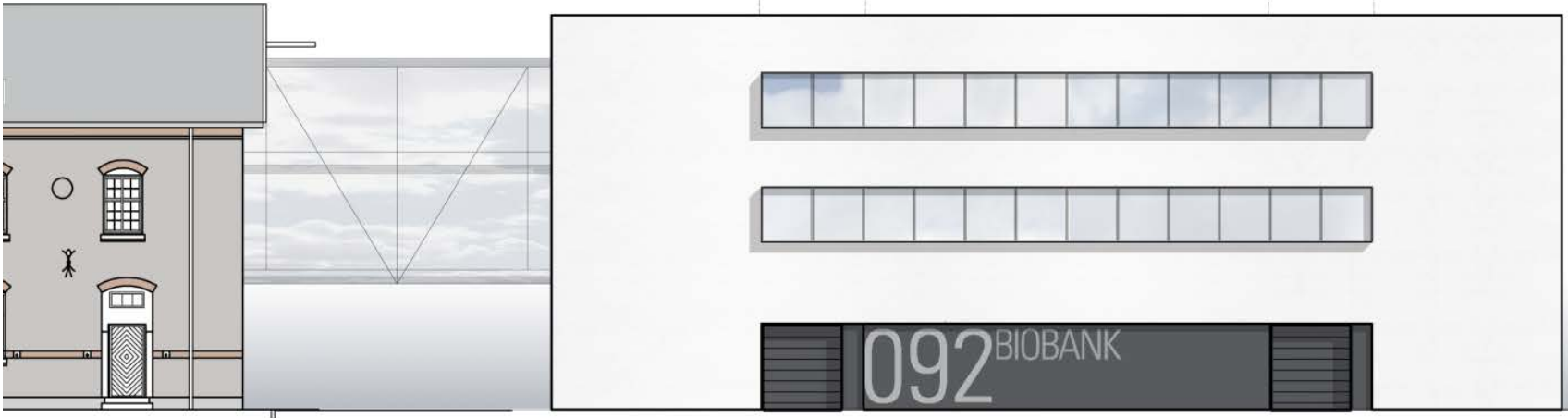
BBMRI.se – a unified Swedish infrastructure for biobanking

WP1 – Project management

WP2 & WP3	WP4	WP5	WP6	WP7	WP8
Collection: Input	Analysis: Output	IT	Physical Facility	Ethics	Financing
Coordinate & harmonize sample / data collection from populations & hospitals	Optimize interface to analysis resources	Enforce a unifying national IT platform	Create an efficient national, large scale sample handling platform	Provide national expertise and forum to address ethical issues	Ensure long-term financing



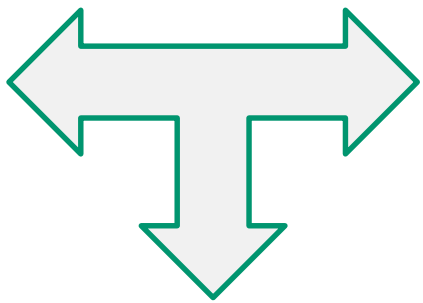
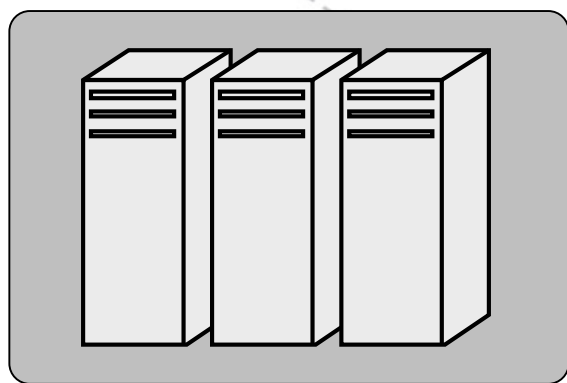
Danish National Biobank facility



National Biobank



National Biobank Register



Coordinating center

BBMRI .fi

BBMRI.fi operates under 8 Work Packages

WP1: Coordination
(Anu Jalanko, THL)

WP2: Epidemiological samples and data
(Markus Perola, THL, FIMM & working group)

WP3: Clinical samples and data
(Tarja Laitinen, VSSH, UTU & hospital districts)

WP4: Sample analysis services
(Services by Biocenter Finland & FIMM Tech Center)

WP5: National IT-infrastructure
(FIMM & working group FIMM, CSC, THL, hospital districts)

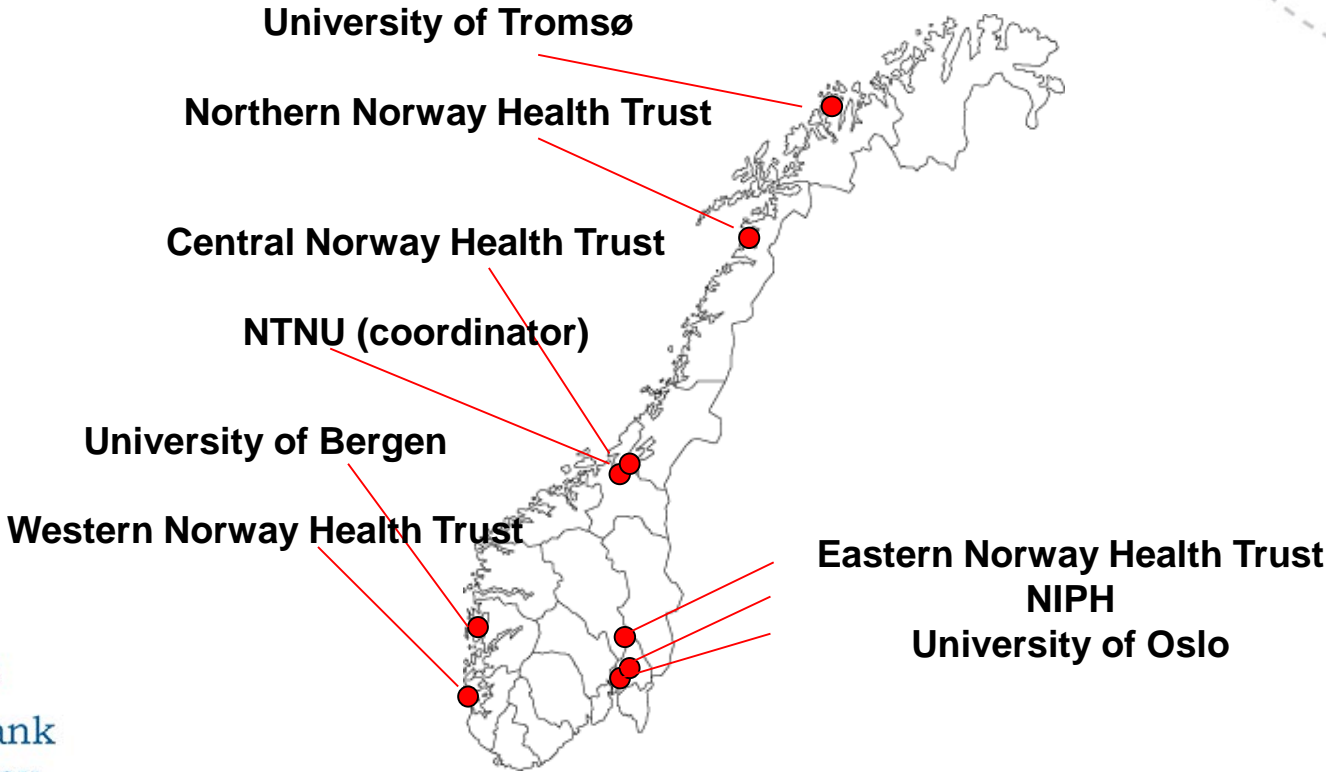
WP6: Biobank technologies & services
(MIBI Biobank Services coord. By Päivi Laiho, THL)

WP7: Ethical and legal aspects and implementation of biobank legislation
(Helena Kääriäinen, THL & working group)

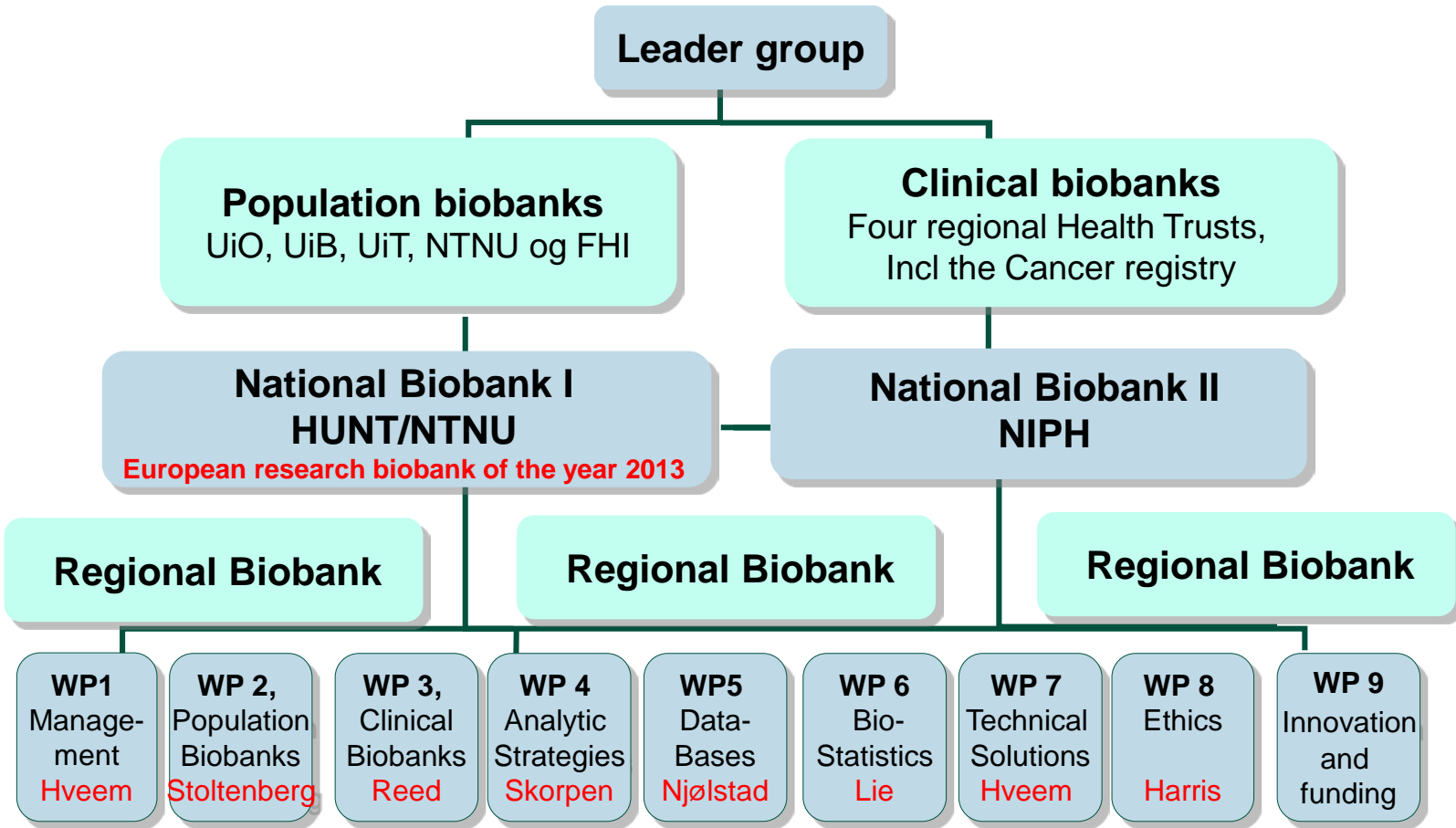
WP8: Public relations
(Kimmo Pitkänen, FIMM & working group)

Biobank Norway

A National Biobank Infrastructure for both population based and clinical biobanks



BBMRI.no – organization and WP-structure



International collaboration

ESFRI-Roadmap/BBMRI

- **BBMRI.eu**
 - Preparatory phase 2007-2010
 - BBMRI-ERIC:
- **Some of the national nodes established**
 - **BBMRI.se**
 - **BBMRI.nl**
 - **BBMRI.no** (Biobank Norge)
 - **BBMRI.fi**
 - **BBMRI.is** (deCODE)
 - **Danish National biobank**
- **BioSHaRE-EU (2011-2016)**
- **BBMRI-LPC (2012-2016)**
- **European Computer Cloud Projects**
- **Horizon 2020**



Major challenges to be discussed

- How to make (population) biobanks useful in clinical trials
- Biobank quality measures
- Biobank catalogues/inventories/LIMS
- Ethics
- Identification of outcome/clinical endpoints
- Involvement of industry
 - Biomarker validation
 - Drug development
- Data storage
- Funding and sustainability

Report on biobank collaboration

- Who will be the user
 - **Clinical researchers** within the health care system
 - Easy access
 - Creates a benefit for the health care system, saving time and money and will have access to **QC**-data and samples
 - **Industry** have shown an interest in both the registries and the sample collection
 - Industrial collaboration is encouraged, ethically approved and already implemented
 - Post marketing studies
 - Effects of vaccination
 - Biomarker validation (Norway – HUNT Biosciences)
 - Industrial companies are knocking on the door of many biobanks (i.e. Finland, Denmark) and are also waving a need and desire to **re-contact** the participants
 - Biomarker validation – will not sell out samples, preferably just data

Industry specific needs

- What is in the bank?
- Insight and knowledge about what the biobank otherwise can offer, also related to various services/analysis
- Re-contact
 - should be organized through the biobanks and not by industry directly.
- Establish RCT based on recruitment from biobanks and registries
 - Will the consent forms allow for recruitment directly?
 - Participate in the planning of new biobank/cohort studies where the consent forms open up for disease based recruitment

Ethical challenges

- Important to collect examples of good and not so good ethical standards/practices – an **ethical “white book”**
- What is a common standard?
- Good governance is as important as comprehensive consent forms
- Communication and transparency,
 - Addressing participants for additional information - 95 000 “personal” letters regarding whole genome sequencing studies – re-enforcing existing consent.
 - Try to be upfront in debating ethical challenges, web site, media, letters
- Ethics is **an active process**, in parallel with changes of the society itself
- We are creating a very comprehensive and powerful research tool with dynamic ethical challenges
- It is unethical **not to use** population biobanks for research since that is the clear and intended will of the participants